

# Open Research Online

---

The Open University's repository of research publications and other research outputs

## Becoming a disabled mother: A qualitative longitudinal study

### Thesis

#### How to cite:

Hadfield, Lucy (2014). Becoming a disabled mother: A qualitative longitudinal study. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 2014 The Author



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000eef8>

---

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

---

[oro.open.ac.uk](http://oro.open.ac.uk)



**Becoming a disabled mother: A qualitative longitudinal study**

**Lucy Hadfield BA MA**

A thesis presented for the degree of Doctorate in Philosophy

Health and Social Care

The Open University

Submitted for examination on August 31 2013

Date of Submission: 30 August 2013  
Date of Award: 26 March 2014

## NOTIFICATION OF REDACTION

**THESIS TITLE:**

Becoming a disabled mother: a qualitative longitudinal study

**AUTHOR:**

Lucy Hadfield

**YEAR:**

2013

**CLASSMARK:**

306.8743087 HAD

The following pages/sections have been redacted from this thesis:

| Page No. | Item/section redacted |
|----------|-----------------------|
| 48       | Photo                 |

## **Abstract**

This thesis seeks to make sense of the complexity of the experience of becoming a disabled mother as made and lived in a dynamic process that is social, embodied, emotional, and temporal. There is limited empirical research that has investigated the experience of disabled motherhood and a relative absence of research that has followed disabled women's processes of identity over the course of the first year of motherhood. This thesis seeks to fill that gap.

The empirical base for this thesis includes material collected from six longitudinal case studies, with disabled women interviewed three times in the first-year transition to becoming a mother. By focusing on what women do with their bodies, or their pursuit of distinct body projects, I reveal insights into my participants' experience and understanding of disability at this stage in the life-course, during which the embodied experience is subject to change and transformation.

Drawing on post-structural concepts of power and agency, I explore the possibilities and limitations within my participants' strategies of sense-making for engineering a liveable life in relation to dominant social norms. These insights speak to a debate within the disability movement about the nature of disability (as experience) as the basis of individual and collective identity and the kind of support disabled mothers need, which can inform social and healthcare practice.

Methodologically, I utilise an innovative psycho-social longitudinal research design and method to enrich and develop my understanding of this process. Researcher subjectivity, difference and temporality are all regarded as important tools for revealing emotional dynamics and processes of intelligibility.



## **Acknowledgement**

Thanks first and foremost to the six women who dedicated their time and commitment to this project. Their determined spirit will remain with me well beyond the close of this thesis. Thanks to my supervisory team: Sheila Peace, Rachel Thomson and Danielle Turney for their teaching, support and encouragement. Thanks particularly to Danielle for scooping me up along the way when I was supervisor-less, and for refusing to let go, and to Rachel for letting me twist her arm to come on board for the latter stages of the research. Thanks also to Melanie Mauthner and Rebecca Jones, who supervised my study in its early stages. Thanks to Wendy Hollway for sharing her expertise, support and feedback in the early stages of my research. Thanks to my colleagues Mary Jane Kehily, Sue Sharpe, Ruth Ponsford, Naomi Rudoe, Jo Sanderson-Mann and Ester McGeeney for their support and encouragement. Thank you to Becky Boyer, Ester McGeeney and Greg Hadfield for commenting on draft chapters and proofreading, and to Fay Coster for her psychoanalytic insight and support. Thanks to Ruth Marchant, and all the Triangle team for sharing with me their inspirational passion and enthusiasm to make a difference to disabled people's lives. And thanks to my family and friends for putting up with me and encouraging me to finish this thesis. Thanks to my mum, dad, and mother-in-law, for being such good grandparents and giving me enough childcare so I could write and think! Thanks especially to my husband for trying so masterfully to talk about Judith Butler and embodiment with me and for keeping me on the right track. Finally, thanks to Joseph for making the bits in between the writing process so fun and teaching me what it really means to become a mother.

## **Contents**

### **Chapter 1: The origins of a research journey to understand embodied difference - *Page 7***

Section 1: Personal and political journeys - *Page 9*

Section 2: Beginning the PhD journey - *Page 15*

Section 3: Outlining the thesis structure – *Page 24*

### **Chapter 2: Navigating the literature on disabled motherhood - *Page 28***

Section 1: Contextualising absences and silences - *Page 29*

Section 2: The construction of disability and parenting - *Page 35*

Section 3: Investigating maternal bodies and identities - *Page 52*

Conclusion - *Page 73*

### **Chapter 3: Mapping the methodological route of the research journey - *Page 76***

Section 1: A QLR Research Design - *Page 77*

Section 2: Psycho-social methodology - *Page 85*

Section 3: A psycho-social longitudinal method of analysis and presentation -  
*Page 101*

Conclusion - *Page 109*

### **Chapter 4: Expecting - *Page 111***

Section 1: Reflections on the past - *Page 115*

Section 2: Conception, pregnancy and the present - *Page 135*

Section 3: Imagining the future - *Page 153*

Conclusion - *Page 162*

**Chapter 5: Early motherhood (0-5 months) - *Page 165***

Section 1: Reflections on the past - *Page 168*

Section 2: Embodied challenges in the present - *Page 176*

Section 3: 'Hiding' emotions and 'coming out' - *Page 192*

Conclusion - *Page 198*

**Chapter 6: One year after birth (12-18 months) - *Page 202***

Section 1: Reflections on the past - *Page 206*

Section 2: Playing with the boundaries of visible and invisible difference - *Page 221*

Section 3: Parallel body projects in the present - *Page 226*

Conclusion - *Page 233*

**Chapter 7: Reflections on journeys into disabled motherhood - *Page 235***

Section 1: Body projects, the intersection of difference and the emotional implications of intelligibility - *Page 236*

Section 2: Embodiment (and emotions), theorising disability and politics - *Page 245*

Reflections on methodology - *Page 257*

Conclusion - *Page 267*

**Chapter 8: Lessons learned and looking to the future - *Page 268***

**Appendix 1: Original research questions - *Page 278***

**Appendix 2: Interview schedule - *Page 279***

**Appendix 3: The circle map - *Page 282***

**Appendix 4: Field-note framework - *Page 284***

**Appendix 5: Information sheet - *Page 286***

**Appendix 6: Consent form - *Page 293***

**Appendix 7: Account of ethical considerations - *Page 296***

**Bibliography - *Page 299***

## **List of figures**

**Figure 1: ‘Alison Lapper (8 Months)’, Marc Quinn, 2000 (marble) - *Page 44***

**Figure 2: Alison Lapper Pregnant (statue), Marc Quinn, Fourth Plinth, Greater London Authority, September 2005 - *Page 48***

**Figure 3: Processes of analysis - *Page 103***

**Figure 4: Directions of analysis - *Page 105***

## **Table**

**Table 1: Sample characteristics - *Page 81***

## Chapter 1

### The origins of a research journey to understand embodied difference

*Her mother looked at her, her eyes wide and cheeks red. The words tumbling out of her mouth resembled a foreign language as she, frustrated, struggled to explain what had happened overnight while Lucy had been sleeping. 'But she is not dead!' Lucy exclaimed. 'Why are you talking about it like she's dead?' Her mother looked at her with raised eyebrows, opening her mouth to speak, not making a sound.*

*Later that year, as the baby slept in her crib upstairs, the family gathered round the television. Ralph had traditionally filmed all of her cousin's births on his camcorder. As they watched the stark white picture on the screen of limbs, sheets and medical equipment, anticipating the moment of the baby's first cry, Mary let out a yelp and ran out of the room sobbing. 'Why is mummy crying?' Eva asked, looking up at Lucy's mother. There was a silence before her mother said, 'She is upset because Jessica is different from other children.' Ralph shot Lucy's mother an angry look before exiting the room in pursuit of his wife.*

(My earliest memory of trying to make sense of disability as a child in 1989)

This chapter begins in Section 1 by contextualising the origins of this thesis both in relation to my own personal history of trying to make sense of disability and by introducing the development of ideas within the British Disability Movement (BMD) and British disability studies. In Section 2, I give an introduction to my study of the transition to disabled motherhood as a key site for understanding the linked processes of temporality, embodiment and identity. I will outline the key aims of the research and set out my research questions, flagging to the reader the way in which these changed over the course of the study. Finally, in Section 3, I will outline the structure of the thesis.

Memories have been used to punctuate this chapter as a way of ‘mediating the relationship of the past with the present’ and illustrating some of the subjective work involved in making sense of disability over time (McLeod and Thomson, 2009, p 23; Crawford *et al*, 1992). These memories are not the product of collective or individual ‘memory work’; rather they illustrate some of the ‘unfinished business’ I brought to my PhD study (Thomson *et al*, 2011; McLeod and Thomson, 2009; Crawford *et al*, 1992, p 154).

### **Section 1: Personal and political journeys**

My memory of my cousin’s birth reflects the overarching idea within our society that disability equates to ‘personal tragedy’, indeed - in this case - one that appeared to draw in the shattered hopes and aspirations of the wider family (Oliver, 1990). Viewing my uncle from a perspective in the present, I understand that the purpose of the event was simply to try to celebrate Jessica’s life, in much the same way that he had with his other children. At the time, however, it was a confusing and strange episode, reflected in the jumble of stark images on the screen and the unusual display of adult emotions. Silence and the struggle to engage with difference are key themes within the memory and it was left to my mother to voice difference and the difficult emotions that had been provoked.

Shortly after this episode, I remember my mother coming home clutching a green, faded pamphlet from the doctors that was supposed to hold the key to understanding what made Jessica so ‘different’ from other babies. This reliance on medical expertise as a means of understanding disability in relation to treatment, care or cure reflects the dominant ‘medical model’ or ‘dominant discourse’ in British society (Oliver, 1996, 1990, Foucault, 1981, 1973). The dominant medical discourse locates ‘disability’ firmly within the individual marking out their bodies or minds as deviant or abnormal (Oliver, 1996; Morris, 1993). Pathological constructions of dependency, risk and vulnerability

are consequently 'continuously performed and re-inscribed', shaping disabled people's interactions with medical and welfare professionals, as will be further discussed in the next chapter (Thomas, 2007, p 98; McFarlane, 2004).

I was 11 when Jessica was born and unbeknown to me at the time there was a strong movement developing within the UK of disability activists and artists who were battling to challenge such 'pathological' understandings of disability and related experiences of social exclusion (Oliver, 1990). Through its campaigning, the British Disability Movement (BDM) posed a rhetoric of 'self-determination' and the right to be 'autonomous' offering disabled people and their families alternative and positive forms of disabled identity (Morris, 2011, p 3). As will be discussed more fully in Chapter 2, the BDM also redefined disability in relation to social barriers and a shared experience of social oppression as opposed to the impaired body or mind (Disabled People International 1982, The Union of the Physically Impaired Against Segregation, 1976). At the same time, disability arts were busy 'affirming' a positive disabled identity now linked to the 'affirmation model' of disability (Swain and French, 2000).

The social barriers or 'social model' approach has led disability studies in Britain and has been conceived as a 'paradigmatic leap' in the way in which disability has been framed in academia in contrast with 'medical model' understandings which had dominated medicine, sociology, psychology and social work (Goodley, 2011, p 11; Olkin, 2009, p 12; Thomas, 2007). As a sociology undergraduate student in the late 1990s, I remember feeling energised by the discovery of Oliver's (1990) early work on the 'social model' through a one-off lecture on social policy. It resonated so closely with my ongoing desire to reject the way in which the birth of my cousin had been socially constructed as the beginning of a life barely worth living. But I was also interested in the emotional work that was going on not only within the family as they



tried to make sense of the meaning and experience of 'disability', but as evidenced in the response of others. As Jessica's cousin my encounters with social attitudes were not at the level of social structures, with medical, educational or social care professionals but in the more everyday settings that formed the backdrop to our holidays and extended family gatherings.

*The room was bright, the sun shining through the thick burgundy curtains. The floor polished wood, wooden chairs around a large table set up for the occasion. A flicker of Jessica's navy dress, with white spots and a red sash. The sense of hushed silence, the heads of other diners hung low or eyes wide, startled, flushed cheeks, watching. She felt confused, she had missed something. Her aunt, angry now, her face contorted, sat at the other end of the table, huddled with Lucy's mother. They muttered together in hushed voices looking round the room. 'For God's sake, this is a family restaurant,' Mary exclaimed. Some of the family get up to leave, but are told to sit down. She picked up her menu and chose her meal.*

(A memory of a family meal as a teenager in the early 1990s)

In this memory, aspects of Jessica's visible embodiment appear to engineer strong reactions in the other diners, evidenced in the 'stares' and 'forbidden' looks (Zitzelberger, 2005; Williams, 1997). In Chapter 2, I will present the way cultural perspectives on disability have enriched British disability studies, highlighting how reactions to the disabled body can be viewed as a product of cultural constructions and unconscious fears and anxiety. My experience at the time, however, appears to be one of confusion, as I fail to make the connection with Jessica's body or indeed focus on anything other than what Jessica is wearing. But the emotive reactions of my aunt stirred a desire in me to make sense of what was being provoked in the silence of the restaurant.

While I had encountered the experience of disability in my family, I had very little knowledge of the way in which other disabled people lived their lives and made sense of their experiences. While studying at university, I worked as a play-worker with disabled children and young people in youth clubs and summer play schemes. I turn now to a memory from that time:

*She sat uncomfortable in the heat, feeling the stickiness of her seat, squashed between a fellow youth worker, Mick (who was driving the mini bus), and Anna. Anna had insisted, doubled over with her hand leaning on the bus (which had been stopped en route back from the outdoor pursuits centre), that they needed to let her sit up front for the rest of the journey. Moments later Anna was poking Lucy in the ribs as she cranked up the volume on the minibus stereo, first a Grease medley then the familiar tones of the Spice Girls begging them to say what they 'really, really, want.' 'Come on Lucy', Anna crowed, beaming at her with big wide eyes, 'Be sexy!' As Lucy reluctantly and self-consciously joined her, their voices simultaneously out of tune, she watched with admiration as Anna tossed her hair and waved her plump arms in the air, her luminous pink-and-yellow plastic dog tag necklaces bouncing off her tight and revealing crop top. Mick laughed and Lucy realised despite herself, that she was enjoying the performance of 'sexy'.*

(A memory of trying to make sense of disability as a young person, 1999)

The relationships I built with young people such as Anna in this time taught me a lot about disability. Many had fragmented home lives moving from one foster carer to the other or lived in families where the opportunity for respite and access to leisure was relatively limited. The 'play schemes' I worked with offered the young people an opportunity to take part in leisure activities such as kayaking, swimming, bowling, watching films in the cinema, hanging out in cafes and on the beach ('play scheme' was

the term used by the charity I worked for to describe the organised activities for disabled teenagers and young people). I witnessed firsthand the discrimination that could occur, such as incidences of direct exclusion from some leisure facilities and the negative attitudes of the general public.

As I will argue in the next chapter, Thomas (2007, 1999, 1997) has made a significant contribution to the field of disability studies and the development of the social model by arguing that the 'social oppression' of disabled people has 'psycho-emotional effects' on their wellbeing (p 8-9; see also Reeves 2006). I could imagine at the time quite clearly how such 'social barriers' and 'disablism' could have a negative impact on young people's sense of identity, particularly in relation to a sense of exclusion from the normative youth culture. I could also imagine the 'psycho-emotional' effects on their wellbeing (Thomas, 1999, 1997; Oliver, 1996, 1990). Yet the body work that Anna appeared to be doing, in relation to her sexuality and identity, marked a moment within my process of sense-making where my understanding of disability and embodiment came unstuck. In that moment, Anna did not appear to be engaging with pathological models or negative cultural constructions of disability; neither did she appear to be acting 'oppressed'. In fact, the freedom with which she appeared to embrace what she called 'sexy' contrasts with my own experience of sexuality as a young woman, which was more self-conscious and inhibited.

It is, of course, a memory of a short moment, and one that occurs within a restricted cultural (youth) setting. I am not suggesting that it actually represents Anna's experience of sexuality across her life-course, or that it speaks back to the experience of all disabled young women. But it remained 'unfinished business' in my process of sense-making at the outset of my PhD study (Crawford *et al*, 1992, p 154). I realised I wanted to understand how women like Anna were making sense of their bodies and

how this related to their identities as 'disabled' people. In the next chapter, I will highlight the recent shift in the field of disability studies (in the past 10 years), from a focus on structural inequality to a more 'critical' examination of the potential of disabled bodies to disrupt normative cultural constructions in society, 'queering' or challenging our normative cultural conceptions of idealised 'sexy' able bodies (Gilleard and Higgs, 2013, p 77; Goodley, 2011; Reynolds, 2002). Can this shift offer a fresh perspective on the experience of being a disabled woman, the way in which disabled women such as Anna claim their identities in relation to non-disabled others?

Returning to my memory of Anna, my role in observing, facilitating and even co-producing the performance of 'sexy' also raised questions about the position my colleagues and I fell into as 'able' individuals. In the next chapter, I will draw attention to the limited work within disability studies that has attempted to address some of the motivations and experiences of professionals and link this to the internalised oppression of disabled people (Marks, 1999, p 110). Was this the position I held?

Does an emphasis on social oppression adequately represent the relationship between all disabled and non-disabled people, all of the time? Or is there something more complex going on?

As Shakespeare (2006) argues,

'To define disability entirely in terms of oppression risks obscuring the positive dimension of social relationships that enable people with impairment' (p 57).

And what use is this binary division between 'us and them' to disability politics if it excludes an opportunity for conversations across lines of difference? For Price and Shildrick (1998) the binaries divisions between disabled/non-disabled self and others reflect the modernist origins of the social model within disability politics:

‘Both personal identity - the sense of a unified, unchanging and bounded self, a base perhaps from which to demonstrate autonomous agency and group identity, with its emphasis on knowing who is to count as the same, seem to manifest a nostalgia for the modernist values of separation and exclusion’ (p 235).

I was left wondering how empirical research can help us uncover the complexity of processes of sense-making both across and within lines of difference while still holding onto the political agenda of the social model.

## **Section 2: Beginning the PhD journey**

In this section I have broken down the key aims and objectives of my research. The aims of the thesis are as follows:

### **1. To raise awareness and challenge perceptions about disabled motherhood**

Starting out on the PhD journey, I was drawn to the absence of ‘disabled motherhood’ within academic literature, and more widely in popular discourse and cultural representations of motherhood. This absence appeared to reflect a long history of denial and exclusion based on ‘a deep-seated antipathy to the very idea of disabled people having children’ (Olsen and Clarke, 2003, xi). My first research aim reflects the agenda of challenging and ‘transforming public and professionals’ perceptions’ about disabled people’s incapacity to care for others and to ‘raise the profile of the parental responsibilities of disabled people’ (Olsen and Clarke, 2003, xi). Crucially, I wanted to contribute to a project of recognising disabled parenting as a human right. A right to be able to make ‘reproductive choices’ with a ‘freedom’ from ‘bias or coercion’, without being restricted by access to information, resources, services or support (Frohmader, 2009, p 4).

My study can be located in relation to a wider political shift driven by disabled parents and the organisations that work with them, to make visible the barriers that disabled women face in fulfilling their parenting role. At the outset of my research there was an increasing recognition of the need to engage with the experiences of disabled parents within the policy framework for maternity service, although significant gaps still remained in relation to adult social care services for supporting parents in their caring role (Morris and Wates, 2006). Responding to the dominance of literature on disabled parenting from a medical model perspective, organisations such as the Disabled Parents Network were working together with the National Family Parenting Institute to ensure that the personal experiences of disabled parents were being translated to inform public policy (Morris and Wates, 2006).

Rather than make generalisable claims about the whole population of disabled mothers, I wanted to build on the existing (but limited) empirical research and literature, generating a rich picture through the intensity of research design and method. My project is primarily an empirical investigation including material collected from six longitudinal case studies with disabled women interviewed three times in the first-year transition to becoming a mother.

## **2. To highlight the importance of temporality for an understanding the body and identity**

The primary purpose of this thesis, however, is to identify what an investigation of first-time disabled motherhood can add to our understanding of disability and its potential deconstruction in relation to embodied norms. It follows that first-time disabled motherhood is significant both as a key life-course moment or stage and as a period in which to examine subjectivity and bodies in transition and that both of these factors can help us understand the meaning and lived experience of disability (Priestley, 2003).

In the same year that I began my PhD study, I also took up a position on the ESRC-funded project 'The Making of Modern Motherhoods', with colleagues Rachel Thomson, Mary Jane Kehily and Sue Sharpe at The Open University. This project was initially part of the ESRC Identities and Social Action Programme (2005-2007) and later part of the ESRC Timescapes Changing Lives Programme (2007-2009). It struck me that the process of 'becoming' a mother was a key time in the life-course in which women were faced with questions about who they were, who they had been and who they would become, but that these questions were also accompanied by new relationships with their bodies over time. I wondered what happened when this process was combined with the process of 'becoming' disabled (Goodley, 2011). That is to say, I am interested in the ongoing identity work disabled women engage with as they faced new embodied experiences of conceiving, carrying, birthing and attending to their babies. As I will present in the following chapter, commentators within the disability field have argued that the idea of a permanent able body is an illusion (Shildrick, 2012, 2005; Wilton, 2003; Price and Shildrick, 1998; Marks, 1999; Wendell, 1996). If we can argue that there is only a 'temporarily able body', should we not also be attending to the temporal experiences of the disabled body (Wendell, 1996)? How does the new embodied experience of motherhood throw disabled women into new relationships with others and in particular with institutions and health social care professionals? How do these embodied experiences complicate women's understandings of what 'disability' means and their sense of identification (both individual and collective) in relation to disability and impairment, gender, social class and other aspects of difference?

### **3. To investigate the limits and possibilities for agency in the transition to disabled motherhood**

I also wanted to investigate both the limits and possibilities for agency in relation to choosing, creating or rejecting identity positions in the transition to disabled motherhood. In my initial research design, I was interested in using narrative to investigate psycho-social processes involved in subjective (conscious and unconscious) investments in discourse positioning as a way of accounting for conformity and resistance to dominant social norms (Hollway and Jefferson, 2000). I was interested in how the experience of the impaired body would complicate these investments over time and the emotional implications of this. Discussion of this approach is extended in Chapter 2 and my original research questions relating to discourse positioning can be found in Appendix 1.

My discomfort with this approach, however, developed through my experience of early fieldwork and analysis. What could be regarded as 'medical model', 'minority model', the 'social model', and the 'affirmation model' all appeared to offer subject positions within women's accounts (a more in-depth discussion of these models will be detailed in the following chapter). It quickly became apparent to me, however, that my data pointed to much richer forms of sense making across women's case studies with a focus on what they were 'doing' with their bodies (Lucey, 2004; Hollway and Jefferson, 2000; Shilling, 1993; Featherstone 1991).

My role as a researcher on the MoMM project exposed me to a shift in the study of maternal identity focusing on the way people 'do' the maternal and in what context (Thomson *et al*, 2011; Elliott *et al*, 2009). I wanted to understand how disabled women were making sense of the body work (or projects) they (and others) had engaged with over time, and the emotional implications when understandings of themselves (as



disabled or otherwise) were disrupted or challenged by new embodied experiences (or of related social barriers). My participation in the ESRC Identities Programme (2005-2009) as part of the MoMM project also alerted me to the significance of the work of Judith Butler, which appeared to offer a more complex and agentic model in which to investigate women's experiences of sense-making (processes of intelligibility) over time (discussed in depth in the following chapter). The question I found myself increasingly drawn to, as my research progressed, was whether the experience of the disabled body generates new creative possibilities for understanding the self and others in relation to cultural norms, mirroring the agenda of critical disability studies (Goodley, 2011; Butler, 2004, 1993).

#### **4. To draw out the intersection of difference in the transition to motherhood**

I also aimed to investigate how the 'intersection' of other aspects of difference plays a key role in this process, whereby my participants' (socio-economic, cultural and embodied) personal histories interact in the transition to motherhood. For example, as I will discuss in the next chapter, it has been argued that the project of motherhood can be understood as 'an expression of social location - arrival and departure points within journeys of social mobility' (Thomson *et al*, 2011, p 4; Thomson and Kehily, 2008; Henderson *et al*, 2007, Byrne, 2006; Lawler, 2000). By combining a 'transversal approach' to intersectionality (which argues for a way of thinking across categories of difference - known as intra-categorical complexity), and the idea of intersectionality as a 'dynamic process' (that takes into account the 'sites' where identities are performed), I aimed to pay attention to the way in which aspects of difference talk to each other in space and time (Yuval-Davis, 2006; Staunaes, 2003). Recognising Grosz's (1994) critique of intersectionality as 'gridlock model' that 'fails to account for the mutual constitution and indeterminacy of embodied configurations of gender, sexuality, race, class, and nation', I wanted to pay attention to women's embodied 'situations' and the

way in which these combined with women's personal histories (Rice, 2009; Yuval-Davis, 2006; Grosz 2004; p 20). That is to take seriously the bodily situations of becoming mother as a series of temporal moments: pregnancy, birth and the relationship with a young infant, using these moments as a means of illuminating both the particular and the common experience held by and between disabled mothers.

### **5. To link the 'intermeshing' of bodies and subjectivities with a 'social model' agenda**

The year 2005 felt like an exciting time to begin my PhD study. There had been an increasing influence of the 'social model' on British politics. The Disability Discrimination Act of 1995 was revised in 2005 to introduce the duty of public authorities to promote equality for disabled people. The Disability Rights Commission (DRC) was established in 2000 and the 2005 report, 'Improving the Life Chances of Disabled People', formalised the use of the social model (PMSU, 2005 in Barnes, 2012). In addition, social model rhetoric could clearly be found in the publications of agencies dealing with disability in the statutory and voluntary sectors (Barnes, 2012; Barnes and Mercer, 2010; Shakespeare, 2006). Yet while the social model message appeared to be building momentum there was also a sense of mounting discontent within disability studies. As I will discuss in the next chapter, feminists within the disability movement and the academy have long criticised the social model on the basis of its neglect of subjective experience, namely for failing to address the gendered and impaired experience of women's bodies (Thomas, 2007, 1999, 1997; Crow, 1996; Morris, 1996). Others have warned how the neglect of embodiment has left discourses regarding the body and impairment to the domain of biomedicine, meaning that these constructions are lacking in political analysis (Hughes and Paterson, 1997).

There is also a sense that only a small minority of disabled people are actually using the 'social model' as a way of making sense of their life experiences (Shakespeare, 2006, p 72). Indeed, it has been found that many disabled people have not even heard of the social model (Rickell, 2006). Shakespeare (2006) declared that the British social model version of disability has reached a 'dead end', drawing out the neglect of the personal experience of impairment and the strict dichotomy between impairment and disability:

'Disability studies would be better off without the social model which has become fatally undermined by its own contradictions and inadequacies' (Shakespeare, 2006, p 28).

Shakespeare's controversial claim spoke to my desire to capture the complexity of disabled people's experience of embodiment and identity in my research. Rather than abandon the 'social model' my intention is to use empirical insights to show ways in which it can be developed and enriched, through an examination of subjective experience over time, taking into account the body, emotions and the intersection of other aspects of difference. As I will explore in the next chapter, my understanding of disability is similar to that of Thomas's 'intermeshing' of the lived experience of impairment and disablism with the 'social conditions that brings them into being and gives them meaning'. It is also similar to Shakespeare's 'interactional' model that takes into account the relationship between individual and structural factors (Thomas, 2007, p 136; Shakespeare, 2006, p 55).

Like Thomas (2007), I see the social model (and the affirmation model) as a platform from which to build theory, but I am also interested in what the empirical insights from my research can say for disability identity politics. As I have already outlined, the concept of social oppression as is often linked to 'social model' or social barriers understandings of disability. My intention is to present a more complex perspective on

the possibilities and limits of agency with a focus on what women 'do' with their bodies (Goodley, 2011; Thomson *et al*, 2011; Elliott *et al*, 2009; Thomas 2007,1999, 1997; Marks, 1999). In addition, by drawing out the complex experience of difference and embodiment in a temporal context, I hope my participants' experiences of becoming a mother can speak to the possibilities and limitations of a collective 'disabled' identity. In other words, I anticipated that the transition to disabled motherhood would have a bearing on the way in which my participants identify themselves as being disabled with implications for their identification with others.

#### **6. To develop a qualitative longitudinal (methodological) approach to disabled motherhood.**

My participation in the ESRC Timescapes Programme as part of the MoMM project alerted me to the significance of methodological approaches to the investigation identities in process that had not been an explicit focus of my original research questions (although it has always been central to my research design; see Appendix 1 for original research questions). Such an approach complements an investigation into intelligibility and takes seriously the importance of researcher subjectivity and interpersonal dynamics in the research process, denoting a 'shift in the way (mobile) subjectivities of both researched and researcher are formed and reflexivity is attributed' (Thomson 2010a, p 4; McLeod and Yates, 2006; Adkins, 2002). I saw the epistemological position of my project as 'situated' in relation to time and historical place and 'partial' emerging from not only my participants' accounts, but also the emotional dynamic and interaction generated with interviews (Haraway, 1991).

In a recent collective working paper on 'intensity and insight' based on empirical work, the value of QLR has been highlighted in relation to its capacity for capturing 'the interplay of psychodynamic, social and historical dimensions of processual phenomena'

(Thomson, 2010a, p 4). By focusing on subjective experience over time and paying attention to emotional dynamics within encounters with others, I wanted to avoid some of the more static, flat and individualistic (as opposed to inter-subjective) images of agency that are characteristic of a purely discursive or textual analysis (McLeod and Yates, 2006; McLeod, 2003; Bjerrum Nielsen, 1996). In doing so, I hoped to generate an exploration of the experience of disabled motherhood as made and lived in a dynamic process that is social, embodied, emotional and temporal. By highlighting how participants (and researcher) made sense of their experiences over time, their attempts to make these experiences liveable and moments in which this can feel impossible, my aim was to map patterns of power and possibilities for resistance in everyday lives.

In the previous section, I described my difficulty in accepting the position as a 'non-disabled' person in relation to my role, or contribution to the social oppression of disabled people. Following this discomfort, I wanted to explore possibilities for researching across lines of embodied difference, mapping moments of connection and commonality and difference. I wanted to find out if embodied difference can be a useful tool for understanding the construction or indeed the deconstruction of disability and whether difference in the research encounter (and research process) could contribute significant insight to this investigation. In sum, can a methodological approach that takes seriously the importance of emotional 'dynamics' and temporal processes capture more complex picture of the making of identity and the construction and potential deconstruction of difference?

The methodological challenge of this research, however, is how to capture the experience of the body as the 'stuff of subjectivity' and present the relational process by which disabled women are trying to make sense of their experiences in the transition to motherhood (Grosz, 2004, ix). Hence, while this project has an empirical focus, it is

also a methodological investigation of the way that attention to embodied difference, subjectivity and temporality can provide a different and productive lens for the understanding of the lived experience of the transition to ‘disabled motherhood’

The final set of research questions central to this thesis are as follows:

- How have disabled women made their experiences of disability intelligible or liveable in the process of becoming a mother?
- How is this process cross cut with other elements of difference?
- What do women’s experiences tell us about the significance of embodiment (and emotions) for our understanding of the social model and its relevance for disability studies?
- What is the significance of time as method?
- How can researcher subjectivity be used to investigate disabled motherhood?

### **Section 3: Outlining the thesis structure**

The structure of the thesis will be as follows:

In the next chapter, I will locate my study within the existing literature on disabled motherhood. I will address the significant gap in knowledge about disabled women’s lived experiences of their bodies drawing out the implications for the way that disability has been constructed in policy and practice. I will then move on to examine the literature that has highlighted the discursive and cultural constructions of disabled maternal bodies. Finally, I will present existing work on the subjective experience of disabled motherhood and ways in which this work can be enriched and extended with an emphasis on temporality, embodiment and possibilities for agency and resistance.

In Chapter 3, I will outline my methodology as psycho-social and longitudinal. I will map my research journey from the point of my research design and methodology,

including my approach to analysis and writing. In the process, I will reflect on some of the methodological challenges that arose in the duration of the study, highlighting my position in relation to current debate about the applicability of clinical concepts and methods to social research and working across lines of difference. I will consider the potential and limitations of my approach and share my experience of the labour involved in presenting a clear picture of psycho-social qualitative longitudinal research data.

In the following three chapters, I will present my participants' journeys into motherhood from the point of 'expecting' a child through surrogacy or pregnancy (Chapter 4), when the babies were approximately four to five months old (Chapter 5) and at the point at which the infants were aged between 12 to 18 months (Chapter 6). In each chapter, I will capture the emotional dynamic through my descriptions of my encounters with my participants' bodies and their interactions with their children, highlighting my position as a curious observer. In each chapter, cross-cutting themes related to my participants' accounts of past, present and future will be highlighted. I will draw out the way in which my participants present significant 'body projects' in relation to their experience of disability and disabled motherhood (Shilling, 1993, Featherstone, 1991). In the process, I document the ongoing identity work of sense making, relating to their sense of self as similar or different from others (Butler, 2004). The motif of in/visibility will be used to investigate patterns of intelligibility within individual case studies of Cathy (Chapter 4), Magda (Chapter 5) and Lizzie (Chapter 6) including the theme of 'passing' which was evident within the emotional dynamic of my interview with Cathy and Lizzie (Butler, 1993).

In Chapter 7, I will reflect on my participants' accounts and evidence arising from the interview dynamic, capturing the significance of process and emotionality for an

understanding of the experience of disability in the process of becoming a mother. By summarising and making explicit the strategies my participants used to make their experiences intelligible, I will evaluate the relationship between these processes and possibilities for the deconstruction and resistance to dominant social norms. In doing so, I will address the question as to how difference intersects with these processes. I will then address the fragility of processes of intelligibility drawing out the emotional consequences of the quest to make a life liveable. I then evaluate the significance of my participants' embodied experience for disability studies and disability politics. Finally, I will evaluate my methodology, highlighting the potential of QLR that draws on psycho-social insights as a means of making the complexity of subjective experiences apparent.

In Chapter 8, I will conclude the journey of the thesis. I will reiterate the contribution my thesis makes to knowledge within the field of disability studies, disability politics, and the increasing body of literature and research that combines qualitative longitudinal research with psychoanalytically-informed methods. I will then highlight future avenues and directions for outputs and further research. Finally, I will address the passage of historical and biographical time since the research data was collected, analysed and written.

This thesis is not only an exploration of academic ideas; it is a testament to - and a record of - the important and valuable work my six research participants committed to the project. Each gave their time and energy in the first year of motherhood, providing a space to produce what often proved to be emotionally difficult and provocative accounts. My participants exposed themselves through the course of the study to sharing the often-unexpected challenges they faced alongside moments of joy and achievement. Each had different motives for participation in the study, ranging from a desire to put their accounts out there for other disabled women to read or to educate policy-makers



and practitioners. What we all share, however, is a wish to tell a 'better story' about disabled motherhood, grounded in women's diverse experiences (Ramazanoglu and Holland, 2002, p 2).

Writing the memories in the third person is a classic feature of the methodological practice of memory work, seen as a way of offering the reader multiple positions for the reader to identify with (McLeod and Thomson, 2009). I hope that, by introducing some of my personal memories in this chapter, I have begun to illustrate the relational nature of disability and the way in which this is dynamic and always changing over time.

## **Chapter 2**

### **Navigating the literature on disabled motherhood**

On embarking on this study, I was struck by the lack of empirical research and commentary on disabled motherhood. This discovery was all the more puzzling given the wealth of sociological and feminist research and literature on motherhood that I navigated on behalf of the MoMM project.

I begin this review in Section 1 by accounting for these absences, also highlighting the way in which early feminist theorising failed to consider the intersection of disability and motherhood. Moving on to explore the literature within the field of medical and clinical research, I show the way in which this absence has reduced examination of the experience of disabled motherhood to assessments of impairment and coping with implications for policy and practice.

In Section 2, I explore the literature within the field of disability studies addressing parenting and the disabled body. I begin with a presentation of the construction of normative expectations of disabled women's bodies related to their capacity for and rights to engage in sexual relationships, dangers or risks involved in reproduction and their capacity to parent. Moving on to focus on concepts of autonomy and dependence I highlight how others have challenged the normative construction of dependency and independence in relation to caring relationships. I draw out the implications of these deconstructions for women's lived experiences of support and interdependency.

I then move on to explore literature within disability studies that has drawn on cultural analysis and psychoanalysis to understand the gendered construction of the visually disabled maternal body. Drawing on existing literature which has examined 'invisible' embodied difference in relation to concepts of 'passing' I question the implications of

the experience of in/visible disabled maternal bodies for women's process of sense making.

In Section 3, I contextualise the core focus of my research: women's experience of becoming a disabled mother for the first time, or the making of identities in process. I begin by drawing on empirical research and personal accounts that have highlighted the psycho-emotional effects of disabled pregnancy, birth and parenting, the experience of the body and possibilities for resistance to dominant (medical) discursive constructions of the body. I then turn to the way in which post-structural and sociological studies of the maternal and the body have developed, with a focus on what people 'do' with their bodies in relation to common culture, the intersection of other elements of difference (such as social class) and finally the potential for 'queering' dominant embodied norms. It is here that I introduce the importance of temporality, in relation to first-time motherhood as a transitional moment in the life-course, the work of 'body projects', moments of disruption, and the process of sense making over time.

## **Section 1: Contextualising absences and silences**

### **The disability movement**

The political culture that forms the basis of the British Disability Movement (BDM) has been shaped by socialist thought with an emphasis on the organisation of work, the distribution of property and concepts of economic and structural oppression (Marks, 1999, p 3-5). The economy and state institutions were seen as playing a key role in this oppression. As I introduced in the previous chapter the BDM politicised the definition of disability by separating impairment as 'a defective organism or mechanism of the body' from disability as the 'loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers' (Disabled People International, 1982, The Union of the Physically Impaired Against

Segregation, 1976 in Goodley, 2011, p 8). By redefining disability in relation to social barriers which exclude disabled people from full participation in society and further by making a claim of the shared experience of social oppression, it has been argued that the British disability movement offered a 'confident positive disabled identity within a broad inclusive disability community'. (Gilson *et al*, 1997 in Shakespeare, 2006, p 68; Campbell and Oliver, 1996). The experience of direct action and involvement in disability politics was seen as offering disabled people feelings of power and validation (Shakespeare, 2006; Campbell and Oliver, 1996). The field of the disability arts and deaf culture also built the 'affirmation' of a positive identity of living with impairment and celebrating their experience of diversity and difference (Shakespeare, 2006, p 69; Swain and French, 2000).

The division of body from disability and the juxtaposition of the individual or medical model of disability with what has become known as the 'social model' of disability became the 'big idea' of the British disability movement (Goodley, 2011, p 11, Olkin, 2009, p 12, Shakespeare, 2006; Hasler, 1993). It followed that 'any conceptualisation of disability that does not view 'disability' as an oppressive social concept and highlight social cultural-understandings can be regarded as coming under the umbrella of the medical model' (Fawcett, 2000, p 17). In contrast, the North American 'minority model' of disability has been said to 'blur' the distinction between impairment and disability, regarding 'people with disabilities' as a minority position with an emphasis on creating positive identity through cultural analysis and redefinition (Goodley, 2011, p 13-14). To an extent, however, these differences have been exaggerated, there are many similarities and overlaps between the two models (Shakespeare, 2006; Marks, 1999).

What is unique, however, is the way in which a social barriers approach historically led disability studies in Britain which was developed to 'accompany the politicisation (of disabled people) and assist disabled people in their fight for full equality' (Goodley, 2011; Thomas, 2004, p 571).

The neglect of women's gendered experiences of disability and motherhood has been the source of much unrest within the UK disability movement, particularly in the late 1980s and 1990s. By separating disability from impairment, it was felt that the disability movement could fight against the pathologising power of medical models of disability. By avoiding a focus on impairment it was hoped that divisions or hierarchies (of impairment) between disabled people could be avoided and the political message of the movement (a focus on social and environmental barriers) would be strengthened (Oliver, 1996).

Feminists within the movement, however, have argued that by moving focus away from the body, the social model has ignored their gendered experiences and the way in which impairment restricts activity in important ways (Crow 1996; Morris, 1996, 1989).

Thomas (1997, 1999) has argued that a consideration should be made not only of the way in which disablism had psycho-emotional effects but of the psycho-emotional effects of the lived experience of impairment. The focus on disability in the public domain, such as environmental barriers and equality within the economic sphere, also ensured a neglect of private life including intimate relationships (Morris, 1993). As Crow (1996) argued, the model was at risk of alienating women from other disabled people. The failure of the 'social model' to account for aspects of the intersection of other aspects of difference such as gender and the temporality of embodied experience has been attributed to the origins of the disability movement, which it has been argued, is dominated by male wheelchair-users whose experience of impairment remained

relatively unchanged (Shakespeare, 2006). Attempts to include aspects of difference within the minority model made reference to multiple oppressions: the 'double oppression' of race and disablism or the 'triple oppression' of race, disablism and gender (Oliver, 1996; Begum, 1992). There is the danger, however, that by claiming unity in relation to oppression in its multiple forms that disabled women become further objectified and categorised, reduced to victims without agency. As Morris (1998) argues: 'I feel burdened by disadvantage and I feel a victim - such writings do not empower me' (p 5).

In response to this debate, Oliver has accepted that the disability movement has been slow to recognise women and the way in which gender intersects with disability (1990). Furthermore, he conceded that the experience of the body (namely the experience of impairment) is important; it should, however, be considered separate from disablism as 'impairment effects' of a model of impairment (Oliver, 1996).

It is my belief that the lack of research to date on disabled motherhood within the field of disability studies is a net result of this particular history of the social model.

Important figures within the UK disability movement, however, - in particular the work of Morris (1991, 1989) Wates (1997), Wates and Jade (1999) - have done much to raise the profile of disabled mothers voices and experiences, with a particular focus on documenting and collating women's personal accounts. Yet, as Olsen and Wates (2003) have argued, these personal accounts appeared to have got lost or have been received with little value in academic and policy research and commentary.

### **Mainstream feminist movement**

While feminists within the disability movement have criticised the absence of the gendered experience, the mainstream feminism movement and early feminist research neglected disabled women's experiences. Part of the project of second-wave feminism

was to challenge patriarchal knowledge, which linked biology (women's capacity to reproduce) with their role as mothers, linking this narrow concept of maternal 'care' with essentialism and oppression (De Beauvoir, 1949). Medical knowledge and early psychoanalytic thought were subsequently critiqued for their role in perpetuating this ideology (Mitchell, 1974). It is surprising that links were not made between this particular form of power and the hold of medical knowledge and associated power and dominance over disabled people's lives. Early second-wave feminism has been widely critiqued for its tendency to universalise women's experiences, to fit with the political project of uniting women, ignoring the diversity of experience between women. Yet, this fact aside, there is evidence within early feminist writing and research that disabled women were not simply ignored, rather they were seen as part of the problem of non-disabled women's experience of oppression. For example, in Finch's (1987) work on women's caring relationships she argued that, for women to be free from caring work, alternative arrangements (care homes) should be made for those they care for, including the disabled. In doing so, she marginalised the experience of those women who both care for others and are cared for themselves, and crucially failed to question the way in which dependency is socially constructed (Morris, 1993, 1991).

### **Dominant medical, clinical and 'social problem' perspectives**

Limited research on disabled parent's experiences from within the disability field or from a feminist perspective has had significant consequences for policy and practice. Research on disabled parenthood has become the remit of medical, clinical and 'social problem' research, meaning that social factors are largely ignored with a focus on capacities and personal attributes. In addition, this impairment driven focus has meant that the experiences of disabled parents have been separated and fragmented into impairment related categories (Olsen and Clarke, 2003).

Medical research has been found to pathologise disabled motherhood, with its focus on whether a woman's impairment will stop her 'coping' with pregnancy and motherhood, the dangers of conditions being hereditary, and what aids she will need to assist her (Thomas and Curtis, 1997, p 202). Such research places emphasis on tasks that parents will need to carry out, such as changing nappies, basing these tasks on the 'capacity to parent' without recognising factors such as the impact of environment or social support (Heslinga *et al*, 1974 in Olsen and Clarke, 2003, p 8). Clinical research has focused on the impact of impairment on children, particularly in relation to parent's capacity to discipline, resulting in social and developmental problems and poor adjustment (LeClere and Kowalewski, 1994; Jamison and Walker, 1992). While valuable for highlighting women's experience of impairment when carrying out every day mothering activities, such research fails to take into account the impact of social factors such as the lack of support for parents, environmental issues or indeed alternative forms of discipline (Olsen and Clarke, 2003).

Similarly, mental health research tends to focus on links between parental mental health and child abuse, with a general neglect of the impact of social factors (Olsen and Clarke, 2003). Research into parents with learning disabilities has shown that they are placed under the most stringent criteria about what counts as good parenting, whereby common aspects of parenting such as minor injuries are closely assessed. Again, such research fails to take into account social support or the impact of lack of parenting role models as a result of institutional living (Olsen and Clarke, 2003; Booth and Booth, 1994).

In their review of existing research into disabled parenting, Olsen and Wates (2003) highlight the way in which agencies have based policy and practice on inaccurate research assumptions centred on these individual (impairment) as opposed to social,



environmental and economic challenges. From this perspective, disabled parents' access to external support and their relationships with professionals and service providers are not seen as 'determining outcomes', but rather indicators of the way in which parents have failed to come to terms with difficulties related to individual impairment (p 9). As a result, agencies and services have made assessments based on the capacity of disabled parents to parent successfully with what Olsen and Wates term as 'too little attention' paid to 'the organisational, economic and attitudinal contexts within which parenting takes place' (2003, p 9).

In relation to welfare support, emphasis has been put on minimising the negative impact of impairment, rather than looking at avenues for social and practical support. As a result, the child becomes the primary client within the family while the support needs of the disabled adult remains invisible. Many have highlighted the lack of joined-up thinking between child and adult services when dealing with disabled parents and their families (Morris and Wates, 2006, Olsen and Wates, 2003).

In summary, this section has highlighted the importance of research which takes into account the lived experience of disabled mothers in relation to both embodiment and social factors and the way in which these are linked through emotional experience (Thomas, 2007; Grosz, 2004). Without it there is a danger that policy and practice turns to dominant medical model understandings of disability (as impairment) and fails to recognise the needs of disabled mothers and their families.

## **Section 2: The construction of disability and parenting**

### **Sexuality and parenthood**

There is a general consensus among those who have written about sexuality, disability and parenthood that disabled women are excluded from normative social expectations

about women's reproductive capacity, their capacity to parent and, moreover, that disabled parenting is actively discouraged and stigmatised (Longhurst, 2008; Prilleltensky, 2004; Meekosha, 1998; Thomas, 1997; Thomas and Curtis, 1997; Wates, 1997; Shakespeare *et al*, 1996). Centrally, this exclusion from gendered social norms relates to wider normative expectations of the asexuality and vulnerability or infantilisation of disabled bodies.

One of the core normative expectations of disabled women's bodies relates to the perception that they cannot, or should not, engage in sexual relationships. The empirical work of Shakespeare *et al* (1996) was prominent in elevating an interest in disabled people's sexual rights and sexual citizenship, reclaiming the personal as political message and putting the private experience on the public agenda. They highlighted the construction of stereotypes of disabled people depicted in relation to a lack of sexual potency and potential. More recently, it has been argued that despite increasing recognition of disabled people's experience within the media, few depict positive representations of disabled people in a sexual context and where present these tend to evoke pity on the assumption that disability signals a lost sexuality (Shildrick, 2012). There has, however, been some attempt by the media to change this, such as the recent and controversial Channel 4 '*Sex on Wheels*' series, which presented four disabled young people perspectives and experiences while coping with restrictions to their sex lives, including the experience of employing escorts for sex (Sex on Wheels, 2013).

Despite evidence of a diversity of sexual experiences, it has been argued that disabled people are subject to infantilisation and are regarded as asexual; a process that has silenced disabled people in relation to sharing their experiences and claiming their sexual rights (Shildrick, 2012; Shuttleworth, 2002). Where disabled people are seen as sexually active, it is associated with sexual deviance such as masturbation in public, or

as a result of sexual victimisation or risky behaviour (Longhurst, 2008). Commentators have concluded that if sexual agency related to potential or actual independent sexual activity is considered the essential element of full adult personhood, 'the net result of associations of asexuality is a denial of the status of active subjects' (Malacrida, 2009, 2007; Prilleltensky, 2004; Wates, 1997; Shakespeare *et al*, 1996, p 6).

A growing body of literature has also highlighted the effects of contemporary encounters with health professionals and the health system particularly in relation to assistance with intimate care, arguing that the manner with which this is carried out can have a detrimental effect on body image and sexuality (Begum, 1992; Longsdale, 1990). Coupled with a lack of appropriate sex education, such encounters have been seen to deny an individual sense of agency or independence resulting in a lack of ownership over their own body (Shildrick, 2012). The result of this neglect has been attributed to a prominence of child sexual abuse, particularly for those children who live in institutions and are isolated from family (Paul *et al*, 2004; Cross, 1998). Others have linked parental attitudes, particularly in relation to expectations of vulnerability and life-long dependency, with the infantilisation of disabled girls. These attitudes have been linked to a history of institutionalisation of disabled children and a deference to medical and clinical authoritative knowledge (Prilleltensky, 2004).

## **Eugenics**

The most widely cited aspect of disabled people's experiences linked to their exclusion from contemporary reproductive social norms, however, is the way in which the eugenics movement has created an 'oppressive discursive space for disabled women and their offspring that constructed them as lacking' (Longhurst, 2008, p 55). Historically, impairment and associated ideas of dependency and weakness has been linked to the poor functioning of a society resulting in infantilisation and genocide (Shakespeare,

2006; Barnes, 1997). Such principles led to the development of involuntary sterilisation laws in an attempt to prevent 'wrongful births' within the USA, based on the assumption that impairments are always hereditary (Pritchard, 2005; Prilleltensky, 2004). While eugenic practice has been relatively absent within the UK policy context, it has been argued that the opportunity for foetal scanning at 13 and 20 weeks represents a continuum of eugenics principles, based on the assumption that impairment will bring about a lower quality of life for the individual and their family. This is seen as having negative implications for disabled peoples' sense of identity and self-worth (Bailey, 1996; Morris, 1996). Shakespeare (2006) has, however, urged caution about this argument, arguing that the link between prenatal diagnosis and eugenics is too simplistic and exaggerated. Nevertheless, it is easy to see without sensitive treatment how encounters with prenatal diagnosis could raise underlying questions for the disabled mother about her own self-worth and her capacity to raise (dependent) disabled children (McFarlane, 2004; Thomas, 1997).

### **Invisibility, surveillance and reproductive space**

McFarlane's (2004) historical and contemporary analysis of disabled women's bodies has drawn together a post-structural analysis of medical authoritative knowledge with insights from social geography to form a socio-spatial perspective to understand their absence from reproductive space. Drawing on a historical review of disabled women's lives in Glasgow and Edinburgh between 1796 and 1910, she argues that the experience of institutionalisation and spatial segregation over time and space has rendered them invisible in contemporary reproductive spaces. McFarlane attributes and links this historical (spatial) denial of women's citizenship and sexual expression and the development of corresponding stereotypes to women's contemporary experiences of being sexually 'off limits' and 'out of place' in reproductive space (p 31). Increased

visibility and experiences of surveillance are prominent for all women in pregnancy, birth and early motherhood. Yet this experience of visibility for disabled women is markedly different (McFarlane, 2004; Thomas, 1997). Making comparisons with the historical element of her research McFarlane (2004) argues that there has been a shift from the surveillance of institutions and associated bio-power for disabled mothers to the experience of the 'gaze' or 'stare' of what she calls 'societal supervisors', who could be anyone from family and peers to medical and social care professionals (p 28).

Surprisingly very little attention has been given to the application of psychoanalytic concepts to the relationships between disabled and able-bodied people in the context of their everyday lives, which could help us understand the complex nature of interactions between disabled mothers and others. Psycho-social perspectives attend to unconscious processes of anxiety, which can be understood as working through discursive practice with implications for individual and group behaviour and social structures and institutions (Lucey, 2004; Walkerdine *et al*, 2001). A notable exception is the work of Marks (1999) who used these ideas to investigate the 'internalised social oppression' of disabled people in their relationships with able-bodied others particularly professionals and carers (p 25). Marks (1999), argues that unconscious fears and fantasies are reflected in the discriminatory treatment of disabled people. Even when professionals may appear motivated by altruism or a desire to care or help, this motivation is often bound up with a sense of guilt, fear or even repulsion, particularly where individuals identify with the experience of vulnerability or a lack of social recognition (Marks, 1999, p 110).

### **Dependency, autonomy and parenting**

I turn now to the idea that disabled people are themselves in need of - or dependent on - care or support and consequently unable to care for dependent children. Olsen and

Clarke (2003) highlight the way that parenting forms a 'position at the intersection of public and private worlds' and while it constitutes one of the most 'private and intimate roles we undertake it is one subject to the greatest public gaze and scrutiny' (p xi). This gaze or visibility is intensified for disabled parents. One of the most emotive debates surrounding dependency and disabled parenting is related to the possibility of their children becoming young carers. Referred to as the 'Cinderella trap', children are constructed as tragic or heroic in media representations, sacrificing their own carefree childhood or experiencing exploitation by their irresponsible, self-centred parents who depend on them for practical and emotional support (Stables and Smith, 1999, p 257). Such negative constructions, however, fail to consider the way in which a reliance on young carers demonstrates the lack of formal support available to disabled parents (Olsen and Clarke, 2003). The image of the 'upside-down family' also ignores the complex ways in which women and their families make sense of, and negotiate, women's role as carers and the receivers of care or assistance (Malacrida, 2008, p 102; Booth and Booth, 1994). Recent calls have been made for a shift away from the equation of disabled parents with the child in need towards more holistic approaches that take into account the needs of all members of the family (Clarke and Lewis, 2008).

### **Challenging the language of 'care'**

The disabled people's movement within the UK has been historically involved in a project of redefining the meaning of 'independence', from embodied concepts of being self-sufficient to concepts of autonomy through choice and control of assistance in everyday life. In this sense dependence is regarded as a product of social factors rather than individual impairment (Shakespeare, 2006). The incorporation of this idea into public policy through the use of direct payments, linked to the independent living fund, can be seen as at odds with the way in which care services have traditionally been

provided (Morris, 2011). Help for disabled people has been redefined away from concepts of 'care' to 'support', whereby 'personal assistance' is presented in 'mechanical and instrumental terms' and the potential for 'emotional links' are not addressed (Thomas, 2007, p 113; Watson *et al*, 2004). Significant shifts in policy in recent years have made it possible for direct payments to be granted on the basis of parenting need (such as childcare), as opposed to assistance with the parent's direct needs (for example, washing or dressing) (Woodin, 2006).

Debates within disability studies have focused on ways of deconstructing concepts of dependency and autonomy related to care and assistance. For example, it has been argued the negative construction of dependency ignore the fact that we are never fully autonomous and are all in some ways dependent on others, a state that has been referred to as 'interdependency' (Wendell, 1996, p 145). Claims to interdependency reflect feminist research on the ethics of care, which negate the idea of the autonomous disembodied individual (Williams, 2001; Fraser and Gordon, 1994). Instead, it is argued that individuals should be viewed as embedded in networks of care and responsibility (emotional and practical work). Disabled women that may rely on the help of others are also embedded in reciprocal relationships with family members (Morris, 1996). It follows that concepts of autonomy should emphasise mutuality, relatedness, and the recognition of the needs of others. Personal freedom is articulated in relation to obligation and morality (Benhabib, 1986; Gilligan, 1982). McKie *et al* (2002) concept of 'carescapes' acknowledges the complex ways in which people deal with the challenges of organising and carrying out care work over time and space, but that this process is restricted by available resources. In the process of caring over time, relationships develop actively or by chance (p 912).

Within post-structural disability studies attempts have been made to disrupt the language of 'dependency' that has been used to describe relationships between disabled person and those who support them through the concept of 'needscares' (Watson *et al*, 2004; Fraser and Gordon, 1994). The concept of 'needscares' builds on the original concepts of 'carescares' and highlights the 'interdependency of mutual needs that is ongoing, processual and anticipatory as well as immediate and contained within specific tasks' and the way in which people need help and support at different points in the life-course (Watson *et al*, 2006, p 345).

Shakespeare (2006) argues that some of the insights from the feminist ethic of care perspective can help enrich the philosophy of independent living as 'it points to the danger of the complete espousal of independence and rights as a goal... disabled people still often depend on good will and mutual aid as does everyone' (Shakespeare, 2006, p 48). Moreover, Shakespeare argues while independent living has transformed choices for disabled people not all value goals of autonomy and choice and what is needed is a pluralist approach to care and support which recognises the diversity of disabled people's lives and preferences, supporting individuals in appropriate ways (p 151). Evidence also suggests that very few disabled people actually have access to formal assistance or support (Shakespeare, 2006). Take-up of direct payments has been found to be low and inconsistent across the UK (Morris, 2003).

Few empirical studies have focused on disabled parents perceptions of formal and informal support and how this can change over time (Woodin 2006; Olsen and Clarke, 2003). Attention to the ongoing and changing nature of parent's needs are found primarily in personal accounts and small studies focused on the role of professionals, such as occupational therapists (Morris and Wates, 2006). Very little, however, has been written about disabled women's experience and understandings of autonomy,



dependency and interdependency as they make the transition to first-time motherhood. The limited literature available suggests that the preserving of autonomy is crucial when assisting women in the early days of motherhood: 'The most effective support is that which helps parents learn for themselves' (Morris and Wates, 2006, p 51). It is recognised that any assistance given in the form of looking after a new-born must be 'provided sensitively to avoid it affecting the bonding process' (Morris and Wates, 2006, p 50).

Anticipation and experience of negative attitudes from social care professionals and fears of professional intervention on the basis of child protection has been seen as a barrier to parents seeking support (Morris and Wates, 2006, Woodin, 2006). In their review of practice issues related to the support of parents with learning difficulties Tarleton *et al* (2006) highlight a vicious circle whereby disengagement from children and family services could subsequently feed into children and family services concerns about parenting ability. Understandings of 'autonomy' and 'interdependency' therefore need to be placed in the wider social context and in relation to women's personal situations as embedded in relationships with others.

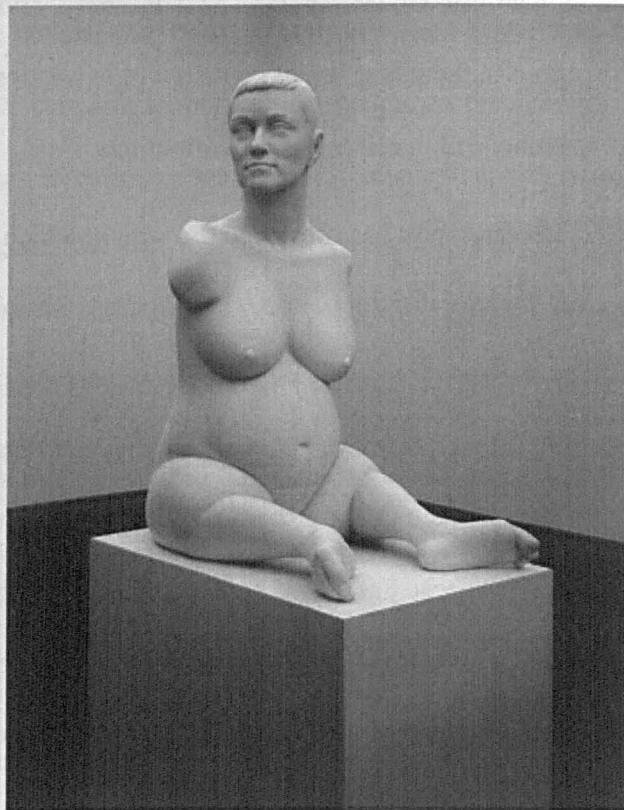
In summary, key literature has presented the way in which disabled motherhood disrupt key normative constructions about dis/abled bodies. Disabled bodies are socially constructed as asexual or sexually deviant and dependent on others. Disabled parents subsequently fit into a discursive space where they are regarded as irresponsible, incapable (of independent care for their children) and in danger of reproducing further undesirable bodies. These discursive constructions are embedded within the structures of social and medical institutions with which disabled parents come into contact, and are reflected in relationships with professionals and service providers, and the type of support and resources that are available making them highly visible on the one hand

(surveillance) and invisible on the other (neglect of needs). Even where professionals may appear motivated by a desire to help disabled mothers there is still the danger that this motivation could be bound up with complex negative (unconscious) feelings with implications for the type of support that can be offered.

Despite attempts to redefine supportive or caring relationships in relation to concepts of 'autonomy' and 'interdependency' there has been very little attention given to disabled women's related processes of sense making in the transition to first-time motherhood, where experiences of autonomy and dependency are potentially subject to disruption.

I turn now to a focus on visual representations of the disabled and maternal body, highlighting perspectives within cultural studies that have drawn on psychoanalytic ideas to understand the way similar messages about bodies are brought into being.

#### **Cultural constructions of disability and maternal bodies**



**Figure 1:** 'Alison Lapper (8 Months)', Mark Quinn, 2000 (marble).

North American cultural perspectives on disability have enriched both the minority and social barriers model of disability by marking 'disability' as a cultural concept (Goodley, 2011; Mallet, 2007). Crucially the 'cultural model of disability', rejects the separation of impairment from disability by drawing out the way in which bodies are saturated with cultural meaning (Goodley, 2011). I have been drawn to the work of those who have investigated cultural representations of disabled bodies (as tragedy or an object of charity) through the lens of psychoanalysis. Disabled bodies are understood psychically troubling, because they represent the vulnerability, fragility and mortality of all bodies (Marks, 1999). This analysis points to the illusion of the able body, in a sense we are all temporarily able-bodied (Shildrick, 2012, 2005; Wilton, 2003; Price and Shildrick, 1998; Marks, 1999; Wendell, 1996). The disabled body is troubling because it breaks with normative understandings of bodies as 'uniform and predictable', whose 'physical reality may be forgotten, save the medium of the autonomous subject' (Shildrick and Price, 1998, p 227). Control of what Shildrick and Price (1998) refer to as the 'gross fleshy disorders' of the body work in parallel to the 'promotion of conformity that characterises the bio/logical body' (p 227). By deconstructing representations in this way it has been possible to reveal the 'disabling mode of cultural production' (Goodley, 2011, p 15).

Consumer culture has constructed images of the 'body beautiful' as 'openly sexual and associated with hedonism, leisure and display' emphasising the importance of appearance and the 'look' (Featherstone, 1991, p 170). Feminists within the disability field have argued that, in contrast to the healthy beautiful reproductive bodies of others, disabled women are seen as unable to make their bodies 'fit' with cultural ideals of beauty (Wendell, 1996, p 91). Drawing on psychoanalytic concepts it has been argued that psychic defences (of splitting and projection) relate to an aesthetic anxiety within a

narcissistic and ablest culture, in which individuals strive for perfection and independence (Wilton, 2003; Marks, 1999).

Images of the impaired body such as those found in charity adverts have been deconstructed in relation to the fears of dependency and debility that are repressed in the unconscious mind of able-bodied people. It follows that these fears that remain unrecognised are then projected onto disabled people (Davis, 1997; Garland-Thomson, 1997; Evans, 1992; Hevey, 1992) Women's disabled bodies have been seen to visually represent or signify 'ugliness' and 'dangerous reproduction' and are subsequently subject to the 'stare' which sculpts them into 'a grotesque spectacle' and an 'icon of deviance' (Meekosha, 1998, p 172; Garland-Thomson, 1997). Zitzelberger argues the objectification of the disabled body renders women as simultaneously seen and unseen (Zitzelberger, 2005, in Thomas, 2007, p 133). This tension between the objectifying stare and contrasting invisibility (from normative representations of the body) has been neatly articulated in relation to race as the 'forbidden gaze', giving a sense of what one is are 'cultured to see or not see' (Williams, 1997, p 5).

It has also been argued that it is not only the visual image of the disabled maternal body that is psychically troubling. Women's physical capacity for reproduction (their female corporality) has also been linked to perceptions of being 'unbounded', and anomalous', 'leaky, uncontained and uncontrollable, 'a disorder that threatens all order' (Shildrick, 2005; Grosz, 1994, p 203). Pregnancy serves as the 'exact antitheses of individuality' our dominant cultural understandings of the individual self with the potential to be unsettling as it challenges conceptions of boundaries between self and other. (Franklin 1991, p 203, quoted in Tyler, 2001). This has obvious challenging implications for encounters with the visibly-disabled pregnant body, which can be viewed as both vulnerable and dependent while conversely holding a dependent foetus. Empirical

research into the pregnant body has demonstrated that this apparent loss of control and embodiment of leaky boundaries provokes a sense of unease in public where pregnant women feel under surveillance and are conscience of the 'stare' resulting in a withdrawal from public space (Longhurst, 2001, p 37).

In recent years, however, there has been an increasing representation of the pregnant body through celebrity images and consumer constructions of the 'pregnant beautiful', seemingly challenging the unbounded image of the pregnant woman (Tyler, 2008).

Cultural analysis of pregnancy magazines has highlighted the way in which women are encouraged to develop narcissistic relationships with their pregnant selves through images of the body beautiful in which the foetus is 'seen and claimed as part of the women's bodies' (Thomson *et al*, 2011, p 59). Central to this project women are simultaneously presented with ways to police (self-surveillance) their bodies in relation to displaying the 'pregnant beautiful' during pregnancy getting their bodies back following and attention to the need for medical monitoring, associated risk and attention to what is normal (Tyler, 2008). Despite this empirical research has demonstrated that, far from the feeling of 'stardom' associated with (normative) visual representations of the 'bump', women's bodies become a form of public property in which normative body boundaries are transgressed, resulting in for some unwelcomed comments or touch (Thomson *et al*, 2011, p 72).

**Figure 2:** Alison Lapper Pregnant (statue), Marc Quinn, Fourth Plinth, Greater London Authority, September 2005.

Working on the MoMM project it became apparent through our cultural analysis of the pregnancy magazines that images of disabled pregnant women and mothers were notably absent (Hadfield, 2005). Close analysis has demonstrated the way in which the bump can be read in relation to an aesthetic register that positions women as respectable or otherwise, particularly in relation to social class and age (Thomson *et al*, 2011). The absence of disabled bodies could suggest that they are excluded from this positioning. When I began my research, however, in 2005, a marble sculpture of 'Alison Lapper Pregnant' was erected on the fourth plinth in London's Trafalgar Square (as depicted in Figure 2). This statue built on Quinn's earlier work presented in Figure 1. Through his combination of subject matter (Lapper pregnant) and material (marble), the artist contrasted the classical ideal of the beautiful static closed body with the 'grotesque body' in process of becoming and change (Betterton, 2002, p 262). Making the link between the pregnant body and disability, Betterton (2009) states:

‘Like disability the spatial taxonomy of the pregnant body is constituted by a juxtaposition of opposites: it is at the same time hidden and exposed, intimate and yet subject to public scrutiny’ (p 42).

The statue provoked media and public speculation, which largely focused on how ‘bold, brave and beautiful’ it - and, by association, the subject as a disabled mother - was (Cooke, 2005, p 10). Lapper herself proclaimed: ‘It puts disability and femininity and motherhood on the map. It’s time to challenge people’s perceptions of these things’ (Lapper quoted in Cooke, 2005, p 10).

The project of ‘Alison Lapper Pregnant’ reflects a shift in ‘ways of looking’ at disability in late capitalism to include ‘the exotic’ and ‘realistic’ images of disability (Garland - Thomson, 2002, pp 66-69) Disabled people like Lapper have become involved in what has been described as projects of ‘aesthetic resistance’ where the disabled body is presented as beautiful because of disability rather than in spite of it (Marks, 1999, p 182). Others within the arts have laid claim to a project of ‘disability chic’ in which visible markers of disability and associations of ‘shame’ are exaggerated and made erotic (Magnet, 2012).

The statue of Alison Lapper can be seen as a form of ‘queering what counts as nature’, de-familiarising the maternal and hence destabilising gendered and sexual norms (Betterton, 2009, p 84):

‘To embrace what is excluded as a space of possibility for different figurations of embodiment may ... .. offer ‘performative images that can be inhabited’ (Betterton, 2009, p 84).

An inherent criticism with this work, however, is the limitation of cultural resources that are available. Sothorn highlights the apparent sexualisation of disabled bodies in recent

aesthetic imagery that appears to be acceptable only when it is made to conform with hegemonic cultural understandings of gender and sexuality (Sothorn, 2007).

### **Invisible difference**

Of course, 'Lapper Pregnant' depicts a visibly-disabled maternal body. But not all impairments or aspects of embodied difference are visible. Would a statue of a deaf mother or a mother with diabetes pose the same challenges? Prilleltensky (2003), Garland-Thomson (1997) and Wates (1997) all argue that degrees of impairment visibility affect social relations. According to Prilleltensky:

'Impairments that are more visible are associated with higher level of social devaluation, even in the absence of any physical limitation' (2003, p 32).

The experience of invisible impairment poses different challenges in relation to the relationship to dominant social norms. Individuals are faced with the question of whether they should make their embodied difference visible or keep it hidden from view. Within the wider field of disability studies (and queer studies) the experience of invisible embodied difference has been understood in relation to concepts of 'passing', 'disclosure' and 'coming out' (Sherry, 2004, p 773). 'Passing' is a relatively familiar concept within medical sociology, used to demonstrate the way in which disabled people present a false self or deny their impairment to fit in with 'normal' society (Goffman, 1968; Davis, 1961). The concept of 'passing' was famously used in Goffman's work on Stigma and the management of a spoiled identity to account for the way in which individuals who are 'discredited' from normal society 'conceal' their difference from others and manage social interactions in the interest of 'normal' able-bodied individuals (1968, p 65). For those disabled individuals who experience invisible embodied difference or are able to conceal their embodied difference, there is potential for 'passing deliberately' and 'passing by default' (Samuel, 2003, p 235). Literature



within the disability field on passing of impairment has highlighted a range of strategies that individuals draw on to conceal their impairment in different social contexts such as the use of clothing (Thomas, 1999). Concealment can also be understood in relation to the 'happy stories' that people tell or the 'silencing' of impairment which may not necessarily be voluntary depending on the social context (Lingsom, 2008, p 7).

Links have been made between invisible impairment and the experience of lesbian sexuality ('lesbian femme') where the process by which individuals 'come out' is more apparent (Samuels, 2003, p 235). While 'disclosure' refers to the ongoing process by which individuals may choose to tell of their impairment in particular contexts and relationships, 'coming out' can be regarded as a more permanent shift in self-perception or presentation, turning shame into pride, and sharing a collective cultural and political disability experience (Lingsom, 2008, p 8; Shakespeare, 1996).

The project of 'passing' has also been linked to the deconstruction of fixed identity categories. Butler's (1993) most famous example of this is in her work on drag as an example of 'passing'. Butler does not focus on 'passing' as a literal performative act. Drag queens are not dressing up to pass as women. Rather, the performance relates to the way in which 'drag' deconstructs fixed identity categories of sex and gender, challenging our conception of what being a woman means. Such performance highlights the disempowered and fetishized role of the marginalised and abjected subject.

Others have highlighted caution with an analysis of 'passing' which focuses on the disabled person's desire to be 'normal' (Shakespeare, 2006; Shakespeare and Watson, 2001). Indeed, empirical research with disabled people has highlighted the way in which people have rejected definitions of disability as either a social or medical model pertaining instead to being 'really normal', as part of 'mainstream youth culture' or by

defining disability in their own terms (Watson, 2002; Priestley *et al*, 1999). As Shakespeare (2006) argues:

'The denial of disability is implicitly based on the rejection of an idea of an exclusive 'normality', and a refusal to be categorised. This approach may be rather individualistic, and may overlook the problems of discrimination and prejudice. But surely it is a legitimate alternative to a minority group approach' (p 74).

There is a sense of agreement, however, across the analysis of in/visible difference that strategies of passing, disclosure and coming out are always temporary and require repetition over time according to the particular situation or context (Lingsom, 2008; Butler, 2004). This process is significant in the context of the increased visibility of all first-time mothers in pregnancy, birth and early motherhood in relationships with health and social care professionals and institutions. How do individuals 'inhabit' different figurations of embodiment? What work do women do with their disabled maternal bodies when they fail to 'fit' with dominant cultural norms? How do they make sense of this in relation to their identity as 'disabled' women? To look for the answers to these questions I turn now to empirical research and personal accounts that have explored some of the lived experience of disabled motherhood.

### **Section 3: Investigating maternal bodies and identities**

#### **Empirical research and personal accounts of disabled motherhood**

Empirical research and personal accounts have reflected the way in which disabled girls are socialised in relation to social norms that outline the expectation that they will or should not become sexually active (Lapper, 2005; McFarlane, 2004; Prilleltensky, 2004). This was particularly the case for those who grew up in institutions; but negative

attitudes were also found present in parental attitudes, relationships with peers and in interactions with health professionals (Lapper, 2006; Prilleltensky, 2004; Wates and Jade, 1999; Finger, 1990). Personal accounts have also demonstrated encounters with medical professionals that underlie the belief that disabled women should not have children through the discussions of abortions and even sterilisation (Prilleltensky, 2004; Wates and Jade, 1999).

McFarlane's aforementioned (2004) study of women's social spatial experiences of disabled motherhood explores women's experiences of feeling or appearing visible or invisible in public space and interactions with others. Her participants presented retrospective accounts of growing up, sexuality, childlessness, pregnancy, motherhood and - for some - giving up their children. McFarlane considers the gaze of what she calls 'societal supervisors' as having a direct impact on disabled women's behaviour to 'comply with what is expected of them', by either confining themselves to home for the duration of their pregnancy or, in more extreme cases, preventing their participation in sexual citizenship, childrearing and mothering (p 29). Drawing on her participants' experiences, McFarlane argues that expressions of their sexuality - as with other marginalised groups - are not straightforwardly permissible in public space, 'considered distasteful and perverse not for public display' (p 190). The disabled women in her research experienced invasive questioning of their reproductive choices, hostility, abuse or ridicule' (p 116). Accordingly, disabled women seemingly 'invade' the gendered spaces of reproduction, birthing and childrearing that have over time become the preserve of non-disabled women. The experience of the participants in McFarlane's study of the way in which antenatal, birthing and postnatal spaces appeared inappropriate for the specific needs of women with impairments reflects other personal accounts and evidence within policy- and practice-related research and guidelines (Clarke, 2009; Topp 2005; Crow 2003). This apparent invisibility within mainstream

space can be juxtaposed with the consuming stare or gaze of others, resulting in apparent feelings of isolation, neglect, fear (of being perceived as doing the wrong thing) and guilt (McFarlane, 2004).

McFarlane's work is an important contribution to the study of disabled motherhood, as she captures some of the complexity of in/visibility both in construction and experience through a (historical) temporal lens. While her analysis presents a fairly negative picture of women's experiences, she does make a claim to evidence of slow but positive changes in social attitudes towards disabled women expressing reproductive choices, raising children, and creating a 'place' for themselves as mothers in contemporary society (p 162).

### **Psycho-emotional effects**

Women's personal accounts have shown how they have to fight for the right to become parents and undergo considerable 'emotional work' to make this liveable (Wates and Jade, 1999; Wates, 1997; Morris, 1993). Empirical research has highlighted women's fears in relation to their interactions with health and social care professionals. In particular, the feeling of being judged or under surveillance has featured prominently in women's accounts. Women have reported feeling particularly vulnerable when attempting to carry out childcare tasks. Professional attitudes have proven to be a deterrent for requesting practical assistance in relation to fears that their children will be taken away from them (Malacrida, 2009; Topp, 2005; McFarlane, 2004; Thomas 1997). Research that has focused on disabled people's experiences of the relationships with those who they employ has highlighted how disabled parents, particularly lone parents, have recruited friends or family. This is done to maintain the sense of 'the house as a home' and due to the belief that as 'allies' they would not question their position as

parent, related to fears that professional involvement may result in their children been taken away from them (Woodin, 2006, pp. 133, 210).

Significantly, Thomas's (1997) empirical study of disabled mothers, investigated her participants' engagement with the 'medical risk discourse' and the pressure they felt to present themselves as 'good enough mothers'. Thomas based her qualitative study on mixed sample of women with a range of experiences from childless but considering parenthood, pregnant women and those with older children. She found that all of the participants in the study had faced the issue of risk in pregnancy either in relation to their own health or that of their unborn child. She argues that medical concepts of responsibility around the passing on of conditions or impairments for example are particularly 'sharp' for disabled women, based on the idea that disabled children cannot have a life worth living (p 627). Her participants appeared to invest in wider social and medical discourses about what constitutes reproductive risks. As a result, they appeared to comply with the view that passing on impairment was irresponsible, resulting in voluntary sterilisation or feelings of guilt if the condition was passed on (see also Clarke, 2009). Thomas states:

'The women's accounts bear witness to considerable emotional work involved in personal encounters with the risk discourse: worry, anxiety, guilt, lost hopes, unfulfilled dreams, spoilt identities' (p 632).

Furthermore, her participants reported fears of being judged as inadequate as mothers in relation to public and professional discourse, which marked children 'at risk'. Thomas argues all women are subject to this discourse and the idea that able-bodied women are not under surveillance is an 'illusion'; she highlights, however, the way in which it is felt particularly acutely for disabled mothers.

Accordingly:

'Living with the fear of losing the right to care for their children forces some mothers to go to great lengths to present themselves as managing normally often at significant personal cost in terms of comfort and physical and emotional wellbeing' (p 635).

Thomas goes on to argue that the failure of medical and social care professionals to ask women what help they need reflects the belief that disabled people are dependent and helpless and those in authority know best. Where inappropriate help, or forced intervention is made it is experienced as a threat and is 'disempowering' (p 635).

Thomas's work on disabled motherhood offers an account of women's lived experiences of disability that goes beyond describing discourse, discursive practice and available subject positions. By introducing the experience of emotions, she has been able to capture a more complex process in which women actively engage with discourse particularly by presenting themselves as coping in relation to the normative ideas of responsible mothering.

One criticism of the Thomas (1997) study, which she herself has recently made, is that her concept of 'disablism' was 'insufficiently embodied' (Thomas, 2007, p 152). While she separately considered the psycho-emotional effects of impairment, she had failed to consider the way in which disablism could become embodied as pain or suffering.

'Psycho-emotional disablism both in its enactment and its effects should be thought of as fully embodied ... (not as) operating as simply at the level of mind or consciousness.' (Thomas, 2007, p 152)

In their study of disabled parenting, Olsen and Clarke (2003) highlight the difficulties of dividing the psycho-emotional effects of impairment and that of disablism. They found

that some parents were able to distinguish between their experience of impairment effects and disablism, particularly in cases in which impairment was stable, predictable or manageable. For others, however, illness and impairment were placed as central to their experience where they felt sadness or distress at not being able to play with their child or lift them when they were upset. Olsen and Clarke also highlight the need for a more intermeshed approach to impairment and disability, arguing binaries that divide impairment from disability can be oppressive both for those experiencing mental distress and for those with physical or sensory impairments. For example, as one mother articulated, the way in which her epilepsy was brought on by physical and mental distress exacerbated by medical negligence and professional failure to take into account a more holistic picture of her experience.

A more intermeshed understanding of disability, embodiment and psycho-emotional effects has implications for disabled parents' relationships with health and social care professionals in relation to asking for emotional support. Watermeyer (2002) makes the particular connection between disabling attitudes and disabled people's difficulty with asking for psychological help. He argues that individuals are locked in a predicament where, if they reveal emotional struggle, they will be discursively incorporated into a homogenising stereotype. Attacking the political agenda of the social model, he argues that the neglect of the emotional effects of impairment particularly mental distress means that individuals have no place to explore their emotions:

'Such ideology has interpellated 'disabled' and 'non-disabled' persons alike into a code of silence which may render absurdly oppressive contradictions surrounding disability related discrimination seemingly sensible, or simply invisible

....

(What is needed is a space to voice) ‘ the meanings and the pain of the mutually constitutive experience of disablist oppression and impairment’ (Watermeyer, 2002; pp 94 -95).

### **Identity, agency and resistance**

This brings me to the central concern of my own work the relationship between identity, power and resistance. Post-structural approaches have accounted for women’s relationship with a dominant medical discourse and a form of ‘governmentality’ that determines deviance and normality in body and mind (McFarlane, 2004; Foucault, 1973). This use of Foucauldian theory, however, tends to highlight a more restrictive account of agency in which individual subjectivity is shaped by surveillance, both through the feeling of being externally observed and subsequent internal surveillance, resulting in conformity to social norms. In doing so, we are presented with a picture of the way in which individuals are disciplined through the internalisation of behaviour codes and the way in which individuals are marked out as different (as unable or resistant to disciplining themselves).

Conceptualisations of disabled motherhood are made true only by people acting on them or believing they are true and the knowledge that is produced through discourse constitutes a kind of power over those who are known (Hall and Gieben, 1992, p 291). Foucault, however, argued that contradictions within discourses carry the possibility of resistance through the formulation of alternative discourses and subsequent positions. The social model can be seen as one such example (Fawcett, 2000; Foucault, 1981). A valid criticism of this approach, however, is the way in which individuals are seemingly reduced to ‘discourse dopes’ with limited possibilities for resistance and particular implications for disabled people who are already in danger of being portrayed as passive (Thomas, 2007, p 39).



## **Making space for the irrational**

Hollway (1984) has argued that Foucault's presentation of the capacity for resistance to discursive production through positioning is too rational and fails to take into account an individual's own unconscious processes in relation to investments in discourse.

Important work within the field of psycho-social studies has demonstrated the way in which psychoanalysis and post-structuralism can be combined to account for the way in which women take up and resist investment positions, taking into account evidence of defensive mechanisms to deal with individual unconscious anxiety (Hollway and Jefferson, 2000; Hollway, 1984). An examination of this process enables an understanding of the way in which discourse is so powerfully reproduced and defended within society. Hollway's work is important as it moves towards a more complex picture of women's subjective experience, highlighting both limitations and possibilities for agency in an emotional context.

Within disability studies, Marks (1999) has used psychoanalysis to understand the way in which individuals respond to negative projections in relation to disability with their own defences against anxiety - for example, withdrawal, exhibitionism or presenting a false self to the external world - something she attributes to evidence of 'internalised oppression' (p 25). She has less to say, however, on the way in which disabled people resist this oppression, arguing that resistance to disabilist projections is evidenced through collective political action, through asserting new aesthetic images of disability, and through presenting narrative accounts: 'Self-representation which both engages with and disrupts disabilist cultures' (p 118)

An emphasis on the 'social model' as a positive identity resource is something that has understandably featured in literature and research that has illustrated the potential and actual psycho-emotional effects of disablism. In the aforementioned empirical research,

attention has been drawn to the empowering effects of participation in the disability arts and the disability movement for women's sense of self in the face of exclusion from gendered social norms (McFarlane, 2004; Thomas, 1997). For those women who may not have access to such identity resources, the opportunity to share personal accounts and the importance of collections of writing and forums, such as that produced by the Disabled Parenting International (DPI) and the Disabled Parents Network, have also been regarded as essential. As Thomas (1997) argues:

'To see the 'risk discourse' as disablist (something which is significant for all women) requires a change in consciousness, which Morris (1996, 1991), Mason (1992) Anne Finger (1990) and others have made. The women in my study, like most disabled women, have not travelled on that journey or perhaps have not had the opportunity to do so. This does not lessen, however, the power of their personal accounts to 'tell of disablism' (p 633).

While the combination of psychoanalysis with post-structuralism enables us to develop a more complex psycho-social understanding of the way in which women live and take up discursive subject positions, agency is still restricted to positions within existing discourse. As a result, we are in danger of reducing all experience that is not evidence of a political knowledge or evidence of narratives of resistance to social oppression. In turn, the complexity of the way in which women make sense of their lives may have been lost particularly for those women who may not have access to political resources or the capacity for self-reflexivity necessary for narrative construction (1997, 1994). Does this really account for the complexity of women's experiences in relation to power and resistance? Are there other methods and resources women draw upon not only to communicate their experience, but also to make their experiences liveable in relation to

dominant social norms? If so, how effective is this process - and what are the consequences, both emotionally and in relation to the experience of the material body?

### **Performances of identity**

Thomas (1997) study of disabled women's maternity preferences and experiences of maternity services revealed particular performances or presentations of self women made to others to make themselves appear to be complying with ideal motherhood. Similarly, in her Canadian study of disabled motherhood, Malacrida (2009) explored disabled women's experiences of negotiating social norms and expectations of good or ideal mothering. She highlights the idea that mothers are:

‘... .. always present, always capable and always nurturant’ and that for all women ‘ideal motherhood remains a socially constructed object of desire and a punitive normative order against which women are destined to fail’ (p 112).

The examination of disabled women's experience in the context of ideal motherhood can be seen to illuminate the tensions that all women experience. Using Butler's notion of ‘performance’, Malacrida presents evidence from her participants' accounts to show the way in which they perform ideal motherhood. While referring to the way in which normative orders relating to femininity and motherhood are embedded in social interactions, she argues:

‘Despite these barriers, however, women with disabilities go to creative and extraordinary lengths in order to be seen as complying with ideal motherhood, perhaps as a way to lay claim to a maternal and sexual identity that society frequently denies them.’ (p 99)

Malacrida's work gives greater scope to the examination of agency, allowing for both positive and negatives versions of performance in relation to social norms of ideal

motherhood. On the one hand she characterises the participants in her study as 'tailoring' their performances, keeping a low profile or over-compensating or hiding their differences where they were not able to perform physical tasks. Others, however, presented more positive accounts in which disability appeared to facilitate their mothering performances. For example, where women had disabled children, they characterised their disability as a resource they could draw on to educate their children. Her participants also highlighted the way in which their children adapted or met them halfway, and creative ways around physical problems.

Such creative performances can also be found in women's personal accounts of disabled motherhood. Others have observed how they are able to spend more time with their children than other women, provide emotional support, and teach their children caring and thoughtful attitudes through exposure to their impairment (Wates, 1997; Campion, 1995). For many within Malacrida's study, however, barriers within the public and private spheres limited their capacity to represent themselves as the ideal mother.

There has been very little consideration within the literature on disabled motherhood of the way in which women have attempted to make sense of their embodied experiences over time. Existing research into disabled motherhood has either focused on one specific moment in motherhood such as pregnancy or asked participants to reflect back retrospectively on their experiences (for example, asking mothers of older children to talk about their past experiences of pregnancy and early motherhood). One exception is the work of Olsen and Clarke (2003) who returned to some members of their sample of disabled parents at a second point within their research where there was a suggestion of future change or disruption, particularly in the impairment experience.

In summary there has been important work and personal accounts within the disability field, particularly the work of Thomas (1997) and McFarlane (2004) that has recognised

the role of the law, state and medicine in regulating and dividing maternal bodies. This work reflects the trend within mainstream feminist and sociological investigations of the maternal particularly in the 1980s and 1990s to recognise the role of the law, state and medicine in regulating and dividing maternal bodies (Lewis, 1992; Smart, 1992; Oakley, 1980). The work of Thomas (2007, 1999, 1997) and Olsen and Clarke (2003) has provided an important space for the reflection on how the experience of the body is intermeshed with the emotional experience of disabled motherhood, particularly in relation to the effects of disablism.

Recently there has been a shift in the field of disability studies away from a focus on structured inequality to one of 'alterity' or 'otherness' and the potential of disabled bodies to disrupt normative cultural constructions in society (of idealised 'able bodies') (Gilleard and Higgs, 2013, p 77). What is now labelled as 'Critical Disability Studies', builds on the cultural model of disability, combining the agendas of class, feminist, queer and post-colonial studies to present disability as a space for 'moments of reflection' and promotes the investigation of bodies as key sites for 'relational, discursive and cultural inscription' (Goodley, 2011, p 157).

The use of the term 'queer' in queer theory not only describes a particular identity but the 'insistence of a critical interrogation of sexual identity both individual and collective' (Reynolds, 2002, p 161). Moving beyond the language of oppression, transcendence and liberation of the Gay Liberation Movement the queer agenda focuses on deconstruction, normativity and transgression (Reynolds, 2002, p 161). Similarly, the impaired body/mind can be seen to 'queer' the assumed naturalness and idealised version of 'able -bodies', drawing out their limitations and refiguring the disabled body as a place of 'becoming, reflection and production' (Goodley, 2011, p 158).

The embodied experience of disabled people can potentially unsettle dominant cultural norms and even offer us 'embodied alternatives' (Goodley, 2011, p 160). Finally, the 'affirmation model' originating in the disability arts connects the idea of queering dominant cultural norms with the celebration of positive difference. This model contrasts with the social model where embodiment is denied (by separating out impairment from disability) and individuals are encouraged to seek equality with non-disabled people on the basis of their similarity (Shakespeare, 2006, p 80; Swain and French, 2000). I turn now to the way in which the study of the maternal has developed with feminist and sociological thinking and research. In doing so, I highlight possibilities for a more complex investigation of women's experiences of becoming a disabled mother.

### **'Queering the maternal'**

More recently (in the past ten years) maternal studies have heralded a turn away from relating the experience of the maternal and maternal bodies to universalising theories of 'oppression'. There has been a call for research which not only regards mothers as subjects within their own rights, but also uses the maternal as providing new ways for thinking beyond the individual (Thomson *et al*, 2011; Baraitser, 2008a):

'Rather than reading the accounts of mothers back to universal models of pathology and development, we are invited to consider how their experiences push them into territory that confounds their own expectations and those of our theories.' (Thomson *et al*, 2011, p 6)

The treatment of 'Alison Lapper Pregnant', as the 'queering' or making strange of motherhood has been seen as part of a wider project that breaks down and destabilises links between biological sex and gender identity (Thomson *et al*, 2011; Shildrick, 2009; Betterton, 2009, 2002; Butler, 2005, 2004, 1993). In this context, there has been a recent

emergence of research which focuses on the way people 'do' the maternal and in what context (Thomson *et al*, 2011; Elliott *et al*, 2009).

### **The 'common culture of motherhood'**

Women's experiences of becoming a mother have recently been explored in relation to a 'common culture of motherhood' (Thomson *et al*, 2011). This common culture constructs women's transitions into motherhood in relation to choice and synchronicity in the life-course and presents women with a chance of creating or making distinct maternal identities through engagement with cultural representations, expert advice and consumption practices (Thomson *et al*, 2011). Today the 'success story' of women's lives in British society highlights birth as the 'apex of achievement for grown up girls' who delay motherhood until education is complete and career well established, where financial security and the right relationship are expected to 'fall into line with this life' (Thomson *et al*, 2011, p 2).

The common culture of motherhood has implications for women's experience of conception (planning), pregnancy (in preparations for birth and mothering), experiences of work, birth (in the context of a national health service that appears to offer 'choice' and possibilities for a 'normal birth'), and the way in which women manage and display their pre- and post-birth body and mothering practices (Thomson *et al*, 2011; Hadfield and Thomson, 2009; Thomson and Kehily, 2008).

It is possible to map an intersection of this common culture with the cultural construction of disability. For example, if choice and synchronicity are such central aspects to the common culture of motherhood, the exercise of such choice is all the more marked in relation to cultural constructions of disabled women as dependent and incapable of autonomy. This intersection between cultural constructions of motherhood and disability in relation to 'choice' also has particular implications in relation to the

intersection of social class as motherhood can be seen as a destination point for some women in relation to social mobility and a departure point for others (Thomson *et al*, 2011, p 4; Henderson *et al*, 2007; Lawler, 2000). A white middle-class identity is seen as the 'norm of womanhood' and 'practices of mothering (are) implicated in repeating and re-inscribing classed and raced discourses' (Byrne, 2006, p 1003).

### **Theorising the body**

A significant aspect of the sociological literature on the body is the relationship between self-reflexivity, what people do with their bodies and consumer culture (Shilling, 1993; Featherstone, 1991). Anthony Giddens (1991) has argued:

'The reflexivity of self in conjunction with abstract systems pervasively affects the body . . . The body is less and less an extrinsic given functioning outside the internally referential systems of modernity, but becomes itself reflexively mobilised' (p 6-7).

This work complements the work on the cultural construction of disabled bodies as it outlines the way in which consumer culture encourages individuals to 'adopt instrumental strategies to combat deterioration and decay and combines it with the notion that the body is a vehicle of pleasure and self-expression' (Featherstone, 1991, p 170). Shilling (1993) draws attention to the way in which individuals in this context create a sense of self as reflexively understood in relation to 'embodied biographies' (p 4). Individuals engage with 'body work' or 'body projects' where the body is seen as 'an entity in the process of becoming; a project that should be worked at and accomplished as part of an individual's self-identity' (Shilling, 1993, p 4; Featherstone, 1991, p 177-178). Bodies are regarded as 'malleable entities' providing the individual with a sense of control in the instability and uncertainty of late modern society in which they feel unable to exert influence (Shilling, 1993, p 5). It is, however, a project that is



‘doomed to failure’ as while bodies are ‘facilitating’ they are also ‘constraining’, marked not only by death (or being temporary able) but in the ‘frequent refusal to be moulded according to our intentions’ (Shilling, 1993, p 5).

Others have drawn out the way in which the experience of the material body can dramatically alter women’s perceptions of their capacity and desire for such body projects (Thomson *et al*, 2011; Warren and Brewis, 2004). Warren and Brewis (2004) describe pregnancy as a unique ‘body episode’ in which women no longer experience their bodies through their mind or have the grounds to ‘cognitively dominate’ their bodies as they did pre-pregnancy. As a result, pregnancy becomes an ‘epiphany’ in women’s lives that intensifies and alters an expectant mother’s sense of embodiment. It ‘sheds light on and fundamentally affects a woman’s relationship with her body’ (p 221).

While it is not named as such, the presentation of ‘body projects’ in relation to consumer culture (which is combined with ‘high cultures demand for ‘self-realisation’ and self-conscious cultivation of style’) can be seen to reflect the normative constructions of the body in Western societies (Featherstone, 1991, p 176). It follows in Featherstone’s (1991) analysis that the pursuit of body maintenance and improvement is more noticeably found within the professional middle-classes suggesting that they have greater access to resources in their pursuit of the healthy ‘body beautiful’(p,186). A consideration of the ‘body projects’ that those who fall outside normative constructions of the body, however, is notably absent in this analysis. What types of ‘body projects’ do disabled women engage in and how is ‘body work’ disrupted by the embodied change of pregnancy, birth and motherhood?

## **Temporality, emotions and the transition to motherhood**

Miller (2005) argues in her study of first-time motherhood that opportunities for self-reflexivity are heightened by life events such as motherhood as a period of 'heightened and intensified reflexivity as attempts to assert or retain individuality and control in a life are made' (p 141). According to Miller, this is because of the heightened changes both bodily and in terms of a shifting sense of self that need to be accommodated: 'Indeed, it may be that self-reflexivity is more intensely practised when embodied aspects of identity and gender are challenged' (p 141). Recent psycho-social research on the experience of the transition to first-time motherhood has highlighted it as a time of 'profound psychological upheaval' as mothers 'came to terms with primary responsibility for a new dependent and vulnerable baby whose demands meant that they could no longer put themselves first' (Elliott *et al*, 2009; Hollway *et al*, 2008, p 1). Marked conflict occurred between the mother's desire to be an autonomous person and caring for her baby, a tension that Hollway *et al* (2008) argue is not static but changes as infants develop physical and social independence. This tension is also marked by the relationships and expectations of others and the experience of returning to work. An examination of the transition to disabled motherhood offers a fresh perspective on the way in which the body is accommodated and lived is through a temporal lens, allowing for the investigation of disruption, continuity and change.

## **Abjection and agency**

I turn now to the way in which individuals make sense of their embodied experience over time and the potential of this process to disrupt dominant social norms. Butler uses the psychoanalytic concept of abjection to account for the way in which certain people are excluded from normative ideas of subject hood. The operation of norms connect the individual to the social, governing the:

'social intelligibility of an action that allows for 'certain kinds of practices and actions to become recognisable ... imposing a grid of legibility on the social and defining parameters of what will and will not appear within the domain of the social' (Butler, 2004, p 42).

Hence, being intelligible means engaging in current forms of 'social recognition' and requires repetition over time. For people to live a 'livable' life, they are constantly involved in a 'struggle with the norm'. This process has psychological implications as normative expectations of identity hold the potential to 'demean, oppress and blight'. Forms of recognition can be either 'affirming' or 'debilitating', resulting for some in what Butler describes as unlivable situations and precarious lives (Wetherall, 2009, p 13). What is of interest to Butler, however, is the way in which those 'abjected' from the norm, those who are not given opportunities for recognition, account for their lives.

As Butler (2004) argues, these individual accounts offer the potential for recognition, as in lying outside the norm such identities maintain a (troubling) relationship with the norm. Butler's work has been used to demonstrate the way in which alternative constructions of identity have been recognised in troubling relationship with the norm, and taken up in popular cultural discourse (Skeggs, 2009).

Butler's work is important because it reflects a shift in identity studies away from the more conventional division of subjectivity from culture or social structure. Rather than restrict possibilities for identity construction to subjective positioning within discursive practice, concepts such as 'performance' and 'intelligibility' allow for a more agentic process in which diverse identity options could also be recognised in particular social context, albeit in troubling relationship with the norm. Possibilities for resistance can hence be regarded through the creation of new and alternative identities, moving beyond the rigidity of a model that looks at psychic investment in subject positions.

Butler's concepts of intelligibility and performance require the mandatory reproduction of a range of normalised practices which:

'cannot be understood outside a process of iterability, a regularised or constrained repetition of norms' (Butler, 1993, p 95).

According to Butler, norms are relatively unstable. In order for norms to have effect they must be repeated and recited, without their repetition (gendered or dis/abled) subjects would not exist. The fact that norms must be repeated creates a space for them to be repeated differently and as such allows for citations that impair the norms they are intended to fortify. Subjection (to norms) and agency are thus linked. Price and Shildrick (1998) argue:

'It is not that performativity can be posited as some kind of choice - it is indeed compelled - but in the repeated citation of a set of conventional practices, there is always the inevitability of slippage. And it is in those cracks that the possibility as well as the limits of agency occur' (p 241)

Thus, through my investigation of the continual production and reproduction of my participants' accounts of identity in the transition to motherhood, it is possible to trace possibilities not only for the reproduction of embodied norms but also for the way in which norms can be reconfigured, contested and potentially transformed.

In the process of engaging with embodied norms through processes of intelligibility are women able to destabilise the category of disability, calling into question its meaning and purpose? Is this a viable way of existing outside embodied norms, particularly when intertwined with the common culture of motherhood? Or are such processes 'fragile and marginal' in the context of the power of discursive practice and health and social care institutional structures and limited cultural resources which have the capacity to render disabled parents as incompetent? (Thomson *et al*, 2009, p 211).

## **Identity and embodied subjectivity (body and emotions)**

Butler's work demonstrates possibilities for combining the discursive with the psyche without reducing agency or the 'ego' to the pre-discursive (natural or essentialist).

While not central to my own analysis, Butler has drawn on psychoanalytic concepts, in particular the idea of 'melancholia', to understand the way the inner way of the psyche works in relationship to prevailing norms of social regulation which are internalised (Butler, 1993, p 234-236). In doing so, she presents gender as neither psychic truth nor surface appearance, but produced in play between psyche and appearance as a form of psychic performativity (Butler, 1993, p 234). Central to this process is what she describes as a desire (to exist and be recognised) which is exploited by regulatory power.

There are, however, inherent (ontological) challenges through combining Butler's particular version of post-structuralism with my own agenda to investigate the lived emotional and material (embodied) experience. Butler has come under fierce criticism for her failure to engage with the material realities of the body (Pearce, 2004; Segal, 1994; Bordo, 1993). She remains silent on the experience of impairment; indeed, she has also been criticised for ignoring the experiences of pregnancy breastfeeding and birth (Thomson *et al*, 2011). The body in Butler's terms is not something that exists outside of or prior to culture:

'The body is never free from an imaginary construction (being) always a cultural sign' (Butler, 1990, p 90).

As a result, it appears in Butler's work that the body is something of a malleable entity that can 'take on limitless embodiments' (Bigwood, 1998, p 103). In relation to her early work, Butler has responded to her critics by stating that she is not denying the necessary and lived experience of the body, or what she terms as 'primary and

irrefutable experiences', neither is she reducing the body to language (Butler, 1993, p 66). She offers no way, however, of acknowledging the body because, she argues, it is only accessible (that is thought, spoken or written about) through language.

These arguments lead me to Grosz's (1994) concept of the Mobius strip a useful metaphor to illustrate the way in which:

'The inflection of mind into body and body into mind... the ways in which through a kind of twisting or inversion one side becomes another...the uncontrollable drift of the inside into the outside and outside into the inside... the torsion of physical interiority and corporeal exterior ... into one another' (Grosz, 1994, p ix).

According to Grosz (1994), the body is not a natural 'pre-social' entity; but it also does not exist as a '*purely* social, cultural and signifying effect, lacking its own weighty materiality' (p 21-22). The linking of the body with the mind can subsequently be regarded as a form of 'embodied subjectivity' (Grosz, 1994, p 21-22). This understanding of embodiment allows for an investigation of the ways in which individuals 'practically engage with, inhabit and apprehend the world in which they live' (p 21-22). As Grosz (1994) argues:

'Being a body is something that we must come to accommodate psychologically, something that we must live' (p 143).

While Grosz's (1994) work has been criticised for the neglect of an analysis of the disabled body (other than as an 'other' to able-bodiedness), it is the interaction between the body, emotions and processes of sense making that I am interested in capturing (Thomas, 2007).

In summary, recent empirical research has clearly recognised the transition to motherhood as a key moment within the life-course in which women's sense of self and experience of embodiment are called into question (Thomson *et al*, 2011; Elliott *et al*, 2009; Hollway *et al*, 2008; Thomson and Kehily, 2008; Miller, 2005). Key aspects of difference such as social class intersect in this process and cultural concepts of 'choice' and 'synchronicity' within the common culture of motherhood can potentially speak to concepts of embodied autonomy and dependence. It is also a time in which the lived experience of the body has the potential to disrupt the type of 'body projects' women are engaged in (Warren and Brewis, 2004). Attention to the way in which the body is accommodated psychologically, allowing for the 'intermeshing' of the embodied experience in this process can be incorporated into our understandings of the way in which individuals make sense of their experience (Thomas, 2007; Butler, 2004; Grosz, 2004). Attention to the body projects that women are 'doing' and the way in which they are also making sense of their bodies (as an iterative process) in relation to normative cultural constructions allows an investigation of the possibilities for resistance or deconstruction.

## **Conclusion**

The dominant theme across this chapter has been that of the in/visibility of disabled mother's experiences from theory and research, policy and practice, medical and social institutions, visual representations, reproductive spaces and relationships with others. Disabled mothers are either subject to pathology and surveillance or hidden from view and subjected to neglect. Moreover, this distinction is blurred as one can be seen as a direct result of the other (the assumption that disabled parents do not or should not exist). This context highlights the importance of contributing to an understanding of

disabled motherhood through the lens of personal experience which does not neglect embodiment.

By highlighting research and literature that has emphasised the 'in/visibility' of women's disabled bodies, I have presented a socio-cultural context in which to understand women's experiences of disability in the transition to motherhood. How do women make sense of their embodied experiences in relation to normative constructions of independence and autonomy and the healthy, reproductive 'body beautiful'? How do women accounts for moments when the in/visible disabled body comes into contact with others: professionals, family and friends, other mothers and members of the public and more widely their experience of medical and social institutions?

Social oppression has been a key ontological feature within such research with the 'social model' or political narratives presented as a potential tool for resistance. In contrast, there has been a significant turn within studies of the maternal and identity away from grand narratives (of oppression) towards the 'doing' of identity and the way in which identities are situated. By drawing on understandings of the 'common culture of motherhood' and further the type of 'body projects' that are available in relation to consumer culture I have questioned what is left for those women whose maternal bodies do not fit with normative ideals (Thomson *et al*, 2011; Shilling, 1993; Featherstone, 1991).

I have drawn out ways in which others in the fields of disability and maternal studies and insights from post-structural and sociological theory have offered ways of understanding personal experience as temporal, emotional and embodied. My intention has been to make a case for a conceptual framework that emphasises in/visibility, body projects, intelligibility (including passing) and temporality, and an investigation of the transition to disabled motherhood which highlights understandings of 'disability' on



their own terms (Watson, 2002). I am also interested in an investigation of emotions and embodiment as women attempt to 'accommodate' their bodies in processes of sense making and the emotional (and embodied) effects when these processes of intelligibility fail (Thomas, 2007; Butler, 2004; Grosz, 2004).

In the next chapter, I focus on the methodological tools I have drawn on to investigate the complexity of these processes and develop a rich understanding of my participants' experiences that can feed into our understanding of 'disability.' It is here that I will develop the relational aspect of my investigation demonstrating how others (namely myself as researcher) are drawn into processes of sense making over time which is both emotional and embodied.

## Chapter 3

### Mapping the methodological route of the research journey

In this chapter, I map the methodological route of my research journey from my project aims through to research design, sample, methods, analysis and writing. In the process, I will reflect on some of the methodological challenges that arose in the duration of the study. I will account for the way in which I managed these challenges, highlighting my position in relation to relevant debates about the production of knowledge and what 'truths' can be revealed in the analysis of empirical data.

I begin in Section 1 by discussing my qualitative longitudinal research (QLR) design, drawing on the work of others who have joined up temporal and psycho-social methodologies to shed light on the construction of identities in process. I will then present my rationale for the composition of my research sample and account for my experience of recruiting my participants.

Combining psycho-social methods with longitudinal research design can offer a creative means of capturing the interplay of different levels of processual data and moving beyond textual analysis. In Section 2 I will outline the way in which I engaged with three different forms of psycho-social methods: the free association interview method, observation and the use of researcher subjectivity. My understanding of how these tools could be best used changed over the course of the research. I will consider their possibilities and limitations in relation to current debate about the applicability of clinical concepts and methods to social research. I will then reflect on ethical criticisms of working across lines of difference in relation to embodiment. Drawing out the relative absence of psycho-social methodology in the field of disability studies I argue that there is potential to enrich research about difference through my approach.

Finally, in Section 3, I discuss my approach to analysis and writing, highlighting how I engaged with subjective data and manage its considerable volume. I consider the potential and limitations of this approach and share my experience of the labour involved in presenting a clear picture of psycho-social QLR data.

## **Section 1: A QLR Research Design**

### ***QLR design***

Qualitative longitudinal research (QLR) in the past has centred on the basis of repeat interview studies, long-term ethnography or the follow up of classic studies (Holland *et al*, 2004). While life history and biographical research has always involved interviewing individuals more than once, it is only fairly recently studies have begun to highlight the importance of documenting and recording the temporal process of change over time (Thomson and Holland, 2003). The recent ESRC Timescapes research programme for example, focused on the process by which identities are ‘forged, sustained, discarded and reworked in relation to significant others’, whereby ‘time is not just conceived of a linear linking of past to future but a more complex multi-dimensional experience connecting time and space’ ([www.timescapes.leeds.ac.uk](http://www.timescapes.leeds.ac.uk)).

Emphasis on complexity and multi-dimensional experience enables a dynamic temporal understanding of social processes, capturing ‘change in the making’ through the combination of ‘time and texture’. In this respect, time is the medium through which data is collected and explored and that which drives analysis and understanding, forging a link between biography and history (Neale and Flowerdew, 2003, p 192). Rather than focus on the final result that is to define how change occurs (or cause and effect), longitudinal approaches place emphasis on process as the experience of a series of evolving sequences of action of interaction occurring though time and space (Saldana, 2003; Strauss and Corbin, 1998). QLR can ‘walk alongside’ individuals over time, a

method of capturing data that Neale and Flowerdew (2003, p 192) have likened to motion film as opposed to static snapshots, providing close-ups, a focus on plot story lines, turning points and defining moments.

A consideration of 'temporality' (the process of change or continuity over time) was central to my research design. Rather than recruit a large sample of disabled women, with the intention of making a cross-cutting analysis of their experience at one temporal moment, I wanted to generate a richer picture of change over a short period of time (or series of moments) using a small sample of six research participants. I felt that by encouraging disabled mothers to reflect back on their own biographies and the past, their experiences in the present and prospective feelings about the future, it would be possible to sidestep the dangers of reproducing flat, static, linear concepts of identity formation and development by showing the way in which identities are formed through a recursive, shifting and uneven process (McLeod, 2003; Bjerrum Nielsen, 1996). This process of capturing the making and remaking of the self over time has been referred to in previous studies as 'the habitus in process' (McLeod, 2003, p 203). Embodied experiences over time inevitably become woven into this process, where both reflection (of what the body once was) and projection (of what it could be) complicate the present subjective experience and the construction of identity in relation to disabled motherhood. An important example of this is the work of Miller (2005) who interviewed three times over the period of the first year of motherhood; at seven to eight months of pregnancy, six to eight weeks postnatal and between eight to nine months. By paying attention to narrative formation in these intervals, Miller was able to map a shift from anticipatory narratives in pregnancy to complex and contradictory accounts in early motherhood and the way in which narratives were re-drawn, reworked and re-narrated eight months after birth. Crucially Miller argues that the embodied experience of birth and early motherhood were responsible for 'the confusion and struggle to

produce recognisable narratives of mothering' in the six to eight week interviews (Miller, 2005, p 110).

Initially, I planned to interview my participants four times, twice in pregnancy and twice one year after birth. The two sets of interviews were designed to occur in close succession. That is I aimed to interview once in pregnancy and follow this approximately a week later with a second interview and undertake the same process one year after birth. My rationale behind this was based on the principles of the free association narrative interview method (FANI) of Hollway and Jefferson (2000), discussion of which I will return to in the next section. Following the prescriptions of this method, the practice of returning to my participants a week after the first interview meant that themes and hunches could be followed up without disrupting the free flow of the original interview narrative. In practice, however, I found this design impractical, as my participants were widely geographically dispersed and it gave me very little time to reflect on the emergent themes in the data. Following pilot fieldwork I abandoned the follow-up interviews, choosing instead to follow up themes across the course of the three interviews. In this sense, my process of reflection was ongoing across the course of fieldwork, analysis and writing.

Allowing for variation due to sample attrition, all six of the participants in my study were interviewed in a series of waves of data collection at the same three key moments in biographical time. That is not to say that all of the participants were interviewed at the same moment in time (with interviews spanning a three-year period) but all were interviewed at equal time intervals in relation to their mothering over the course of approximately 15 months: in the third trimester of pregnancy (or while expecting through surrogacy); approximately four months after the birth of their first child; and approximately one year after birth (see Table 1). In this sense, I have sampled key

moments of life-course 'transition' (broken up into three distinct stages) as a way to place my participants' experiences in 'conversation with one another' (Thomson, 2007, p 573). Interviewing in three separate waves of data collections also allowed for a body of evidence - an 'archive' or personal history - to be accumulated in which prospective and retrospective questions about the self can be checked and compared, allowing patterns to emerge and an exploration of what people say in relation to what they actually do across a period of time (Thomson, 2007; McLeod, 2003). The timing of my research encounters with my participants reflected embodied and developmental change, both in their physical experiences of pregnancy and the activity of care in relation to the child's development. Culturally, these elements of growth and development are typically regarded as a form of linear progress through time. My choice of interviewing my participants four months and one year after birth reflected the research design of two longitudinal studies on motherhood (Hollway *et al*, 2008; Miller, 2005). Both of these studies emphasised key developmental moments for mother and child such as the recovery period following birth (6-8 weeks) a consideration of weaning (usually occurring between four and six months), alongside more social aspects of change such as being discharged from the care of health services following birth or the return or preparation to return work after maternity leave.

At the time I began my fieldwork, however, in late 2005, changes had been made to maternity leave policy, extending eligibility for maternity leave to 52 weeks (Smeaton and Marsh, 2006). In addition, the NHS had also extended the recommended period before beginning weaning to six months. Nevertheless, as will be explored in the following three data chapters, both themes of returning to work and weaning were revealed through my temporal framework. More generally as will be revealed, by interviewing my participants when their babies were approximately four months old, I

was able to capture some of the ‘temporary confusion’ of the embodied challenges of caring for a young infant Miller (2005, p 89).

**Table 1: Sample characteristics**

| PSEUDONYM OF PARTICIPANT | *DESCRIPTION OF HOW DISABLED  | **AGE | MARITAL SITUATION             | OCCUPATION               | ROUTE TO BECOMING A MOTHER | Wave 1         | Wave 2 | Wave 3 |
|--------------------------|---|-------|-------------------------------|--------------------------|----------------------------|----------------|--------|--------|
| Vanessa (PILOT)          | I am not registered disabled but as I am paralysed due to spinal cord injury this means I am classed as having a disability   | 40    | Single (but plans to cohabit) | Helpline Operator        | Pregnancy                  | 09/06<br>09/06 | N/A    | N/A    |
| Cathy                    | I was born with a congenital heart defect, after having surgery aged 4 to correct this – I had a stroke that left me with a lack of use in my left arm and weakness in my left leg  | 38    | Married                       | Youth worker             | Surrogacy                  | 10/06<br>10/06 | 02/07  | 11/07  |
| Amanda                   | I have rare growth condition 3M syndrome  | 35    | Married                       | Youth worker             | Pregnancy                  | 08/07          | 12/07  | 01/09  |
| Kirsty                   | I have Complex Regional Pain Syndrome(CRPS)/Reflex Sympathetic Dystrophy (RSD), which was caused after spraining my ankle. I am now left with chronic and severe pain in left lower limb. I also walk on the outside of my foot, if I am not wearing my splint. I Walk with a stick on a good day, and with crutches or chair on bad days | 30    | Married                       | Speech Therapist         | Pregnancy                  | 10/07          | 03/08  | 02/09  |
| Magda                    | Hemiplegic Down the Right-side after the removal of a Brain Tumour as a child   | 32    | Married                       | University Administrator | Pregnancy                  | 06/08          | 01/09  | 08/09  |
| Lizzie                   | I have severe psoriatic arthritis, which mainly affects my spine / hip joints / neck  | 35    | Single                        | Unemployed               | Pregnancy                  | 10/08          | 02/09  | 11/09  |
| Amy                      | I am profoundly deaf and use lip reading and speech/sign language to communicate. Have to use a cochlear implant to understand sounds   | 25    | Married                       | Physiotherapist          | Pregnancy                  | 07/08          | 12/08  | 10/09  |

**Information:**

**\*Description of how disabled:** This is based on an initial screening questionnaire response to the question: Can you describe why you consider yourself to be disabled or why you think others consider you to be disabled.

**\*\* Age:** This refers to the age of my participants at the point of the first interview.

**\* Fieldwork:** Wave 1 = Interview in late stages of pregnancy. Wave 2 = Interview 4 months after birth. Wave 3 = Interview 1 year after birth.

***Access and sample composition***

Access to my sample was made in an opportunistic *ad hoc* manner. I had anticipated that it would be difficult to access disabled mothers, as literature on disabled parenting had highlighted their absence from official records (Olsen and Clarke, 2003). In addition, the absence of disabled women coming forward through NHS antenatal services for the MoMM project (even where specifically requested through midwives) alerted me to their possible invisibility within these services, perhaps attributed to their wish to avoid professional surveillance.

My first two interviewees, Vanessa (pilot) and Cathy, were initially recruited as participants for the MoMM project in 2005; they also agreed to take part in my own study. They responded to a specific advert for the MoMM project on a disabled parents' website, but they were also sent information on my own study with their permission. In addition, I posted an additional request for participation on the forum noticeboard of a disabled parents' website. The use of this website enabled me to avoid any of the ethical issues associated with going through a professional service (gatekeepers). This was particularly pertinent for one of my participants, Kirsty, who appeared anxious, questioning whether her account would be relayed to her midwife.

Due to the timescale of my part-time PhD study (from 2004-2013) and the longitudinal nature of the research, the five remaining participants were recruited over the course of a three-year period (from 2006-2009), four of whom responded to the same forum post, requesting further information. In addition, one of my participants (Amy) was accessed through a process of snowballing through another participant (Magda) who had met her via a (mainstream/non-disabled) mothers' internet chatroom. Most of my participants all considered themselves 'disabled' (albeit in a complex way) and came across my advert while seeking online information and support. One of my participants was Amy, a 'deaf mother', and - as will be revealed - her identity in relationships to disability, 'deafness' and Deaf culture was more complex. While Amy saw herself as 'deaf', she did not want to be defined by a deaf identity or as a disabled woman. Amy did not use the website for disabled parents, preferring instead more mainstream websites and forums for (all) mothers.

Each participant was sent a screening questionnaire to access basic information and permission for further contact details to be sent before initial contact was made. Due to the longitudinal nature of the research, access was an ongoing process during the



fieldwork period. Despite the dangers of sample attrition in longitudinal research, only my pilot participant (Vanessa) dropped out of the study, as she felt the intensity of the research method would be too much after the death of her father. As can be seen in Table 1, however, it was sometimes difficult to stick to the temporal stages of the research in cases where contact was temporarily lost (due to moving house or return to work).

### **Sample composition**

My sample represents a particular group of women most of whom used a disability website and forum which offered support and information. In some cases through the duration of the project some of my participants became increasingly involved in this support network (website) on a political level. With the exception of my pilot interviewee none of my participants had formal personal assistance or support before pregnancy. My sample is therefore a relatively 'normative' group of disabled parents in the sense that they were not defined by their use of a particular service or pre-determined as a 'social problem' (Olsen and Clarke, 2003, xi).

All were educated, five of them to degree level; five came from predominantly middle-class backgrounds. As outlined in Table 1, all my participants were white; four were employed in professional work. Five were married and co-habiting. With the exception of Amy, all of my participants were over the age of 30. Part of my strategy for sampling was to generate understandings of disability on my participants' terms and avoid attempting to create diversity on the basis of impairment. In their screening questionnaire women were asked:

'Can you describe why you (or others) consider yourself to be disabled?'

As can be seen in my participants' responses in Table 1, all answered this question in relation to their impairment or health condition. All had some form of physical impairment (as opposed to a learning difficulty or mental health difficulties), although their impairments differed.

Despite these homogenising factors, aspects of unanticipated diversity arose in ways that did not always correlate with traditional sociological categorisations of difference (race, social class, age). Lizzie, for example, identified herself as strongly white middle-class, but could be characterised as experiencing rapid downwards social mobility, experiencing unemployment, homelessness, single motherhood, and dependency on benefits in the duration of the project. Or, to take another example, Cathy became a mother through the route of surrogacy and adoption, providing a different case for assessing her relationship with her body in the transition to motherhood. Geographical location and accessibility also has the potential to impact on disabled women's experiences particularly in relation to visibility and invisibility in their accounts of their interactions with others. These more subtle aspects of difference reflect the complex ways in which different aspects of subjective and material bodily experiences, women's personal biographies and socio-economic circumstances are 'situated' (Thomson *et al*, 2011).

In my feedback from the Open University Human Research Ethics Committee, they asked me to consider the fact that my sample would be 'skewed' by virtue of the recruitment sample and how I planned to report this. This point takes me back to the principles of QLR research as providing insight through intensity (of design and method). Rather than make generalisations, I sought to engage in theoretical analysis using the case-study data; it is the quality of this theoretical reasoning and how well the data relates to theory that is paramount. Case studies, however, are often used as a

starting point for a more intensive investigation, with a wider sample or a more targeted research sample. I am aware, for example, that all of my sample have some form of physical impairment as opposed to learning difficulties or mental health issues with implications for the understanding of embodiment and emotions. This is related to the difficulty of accessing my sample in such an ad-hoc manner rather than an intention of my research design. What my study can do is provide a different theoretical and methodological template for further research with specific groups.

## **Section 2: Psycho-social methodology**

Psycho-social methodology recognises the role of the unconscious in the construction of reality, interpersonal dynamics, the generation of research data and the construction of the research environment (Clarke and Hoggett, 2009).

In the initial formulation of my research design and research questions, I was interested in both the 'defended subject' - as in the work of Hollway and Jefferson (2000) - and the 'defended researcher', in the work of Walkerdine *et al* (2001). Both concepts entail an investigation of how the 'affective' has been developed (Hollway and Jefferson, 2013). This means a move beyond the discursive level of research to take into account unconscious defences against anxiety, which may influence what gets talked about in the interview, and attention to the thoughts and feelings that are stimulated for the researcher, before, during and after the interview. Central to this approach is a consideration of the conditions of the research process, and means of enabling an 'inter-subjective space', otherwise known as 'potential space', a 'third space' or a 'space for emergence' of unconscious processes (Clarke and Hoggett, 2009; p 16). Mirroring clinical practice both in relation to group analysis and one-to-one consultations, it is thought necessary that interviews or research encounters must enable space for a 'free

association' of narrative and emotional response as a way of accessing unconscious material.

### **Free association narrative interviews (FANI)**

The work of Hollway and Jefferson (2000) centres on the process of attending to discourse positioning in relation to unconscious investments, via close examination of the interview transcript data and (although arguably to a lesser extent) the emotional dynamic produced within the interview. By doing so, they argued it is possible to reveal ways in which the 'defended subject' invests in particular discourse subject positions. In their book 'Doing Qualitative Research Differently', they prescribe a number of criteria that make possible the generation of free association narratives within research interviews they have termed the Free Association Narrative Interview (FANI) method (Hollway and Jefferson, 2000,2013). The FANI method differs from other narrative approaches because by using techniques such as open ended questions, it offers a way of limiting the agenda being set by the researcher, facilitating the interviewee's meaning frame, thereby reducing the potential for the suppression of people's stories and maximising the revelation of unconscious dynamics as participants (and researchers) attempt to avoid internal anxiety.

Based on the FANI method, I designed three separate interview schedules for each stage of the research process containing no more than four open - ended interview questions (see Appendix 2, for interview schedules and my rationale for their use). Following the interview I also made notes of key themes or phrases to follow up or attend to in our next encounter and any changes or inconsistencies that I would ask my participants to reflect on. In addition, to avoid probing my participants to talk about interactions and relationships with others directly, I used a 'circle map' as visual prompt. This allowed my participants' time in the interview to assess the influence of significant people in

their lives and to stimulate stories about relationships and encounters (see Appendix 3 for an illustration of the circle map, information on how it was used and developed).

The FANI method was successful in eliciting free-flowing narratives within the interview and providing a wealth of rich data for all of my research participants. A common critique of narrative methodology, however, is that not all participants are good storytellers or reflexive beings (Adkins, 2002; Lawler, 2000; Skeggs, 1997). I became aware that in many cases what could be interpreted as evidence of repressed defences (for example unusual gaps in the narrative, silences and slips of the tongue) in a textual analysis of interview transcripts could simply be a mirror of my participants' particular embodied situations. The practice of generating free association narratives was exhausting not only in relation to my participants' situations as heavily pregnant women but also in relation to their experience of their impairment. My pilot interviewee Vanessa appeared to find the process of telling stories physically demanding. In our first encounter she told me she was not used to talking so much and eventually the interview had to be abandoned because of physical discomfort. My interview with deaf mother Amy was conducted largely through her capacity to lip-read, her ability to hear some sounds through her cochlear implant and more visual forms of communication (gestures, facial expressions etc.). Amy often told stories in a stilted, generalised and factual way and sometimes misinterpreted or misunderstood my questions. I wondered if, as a deaf woman, this seemingly stilted interaction was typical of Amy's experience of communication with non-deaf people: you need to be factually clear in order to get your point across rather than a product of emotions. With babies present in the second- and third-wave interviews, adherence to a strict free association interview method also became more difficult as my participants would break off to interact with their child.

I found that in these cases the detailed descriptions I made of the interview setting and non-verbal communication and interaction in my field notes were invaluable for building some of the context of my participants' situation. Observation as a psycho-social technique is based on non-verbal, embodied aspects of communication and mental states and allows the observer to pick up on what is unsaid or unsayable (Hollway, 2009). In Hollway's (2009) recent research, she draws on infant observation methods as a means of moving beyond the limitations of interview narrative approaches to explore the embodied aspects of identity:

'(Observation) enables us to see identities that are less the product of conscious intentional production through narrative, more sensitive to affect, to unconscious inter-subjectivity and to embodied aspects of identity' (Hollway, 2009, p 334-5).

It was during my Wave 2 interviews, that I came to realise the full value of paying greater attention to the activity in the interview dynamic, particularly interaction with the baby. This value was particularly in relation to everyday activity, such as breastfeeding, play, and nappy-changing, that would often take priority over the interview itself, which was at times too impractical and tiring for mother's to follow. This activity inevitably played into the emotional dynamic between participant and researcher and also child, providing useful data which I recorded retrospectively in my fieldnotes shortly after I left the research encounter.

It would be impossible to replicate the infant observation method without considerable clinical training or access to a trained team of infant observers, and I do not pretend I have done so. The data, however, produced in my observations helped build a rich picture of every day experiences, often going beyond what was able to be expressed in words or in some cases providing a sense of contradiction to the interview narrative provoking new avenues for analysis. That is not to say that one version is more 'true'

than another, but an example of the difference between the presentation or performance of self through narrative and a more complex performance through the interview (emotional) dynamic (Hollway, 2009).

I began to recognise in the early stages of my fieldwork, however, that by using the FANI method that is inspired by clinically observed phenomena and drawing on vocabulary in which I had no professional training I felt consumed by a sense of its authority. My early field notes were full of my own worried musings about when the free association narrative actually began (on the telephone, by email or even in the car as I was given lifts from the station), whether I was following up themes in the right way (in some cases following the linear order of their biographical accounts when my participants paused and in others following up the point at which the narrative appeared to digress in unexpected places), and when to follow up themes from previous interviews. Together, these factors suggest a concern with control over the interview.

My reflections on these tangles of my own making were hugely productive and enabled me to distinguish the types of insights I was looking to generate. My desire to focus on the linear progress of narratives (following up themes from birth to the present), reflects what Saldana (2003) regards as a Western affliction for linear time, progress and development that all researchers should guard against. Rather than use the FANI method in a strict prescriptive way, as a means of closely attuning myself to evidence of my participants' 'defences' within the interview transcript, I began to realise that the value of the method was in relation to its capacity to take the researcher into unexpected and unknown territory. By focusing on moments of discomfort and challenge or conversely comfort and ease (including a desire to control the interview encounter), I found myself able to question and explore some of the emotional work going as

evidence of the way in which both researcher and researched were struggling to make sense of experiences of difference.

### **Researcher subjectivity**

Responding to criticisms of their work in a recently revised and updated edition of *Doing Qualitative Research Differently* (2013), Hollway and Jefferson have admitted that they had not previously given sufficient attention to an analysis of the defended researcher in their work. Indeed, my sense was that in the first edition of their work they regarded attention to researcher subjectivity as a means of guarding against 'conflictual forces' in the production of a pure FANI method and linked analysis of data (as opposed to attention to researcher subjectivity as a source of data in itself) (p 7). The newly revised edition outlines developments in their work in line with a shift towards the affect in the past decade in the field of psycho-social studies, something they regard as a 'momentous change' away from the dominance of discursive perspectives (p 166).

Clarke and Hoggett (2009) argue that researcher subjectivity as a source of knowledge is now a central tenet of all psycho-social approaches to research that holds at their heart 'the reflexive practitioner' (p 7). Psycho-dynamic concepts used primarily in the consulting room of psychotherapy, such as projection, interjection, transference and counter-transference have been regarded as important tools for social scientists as by their very nature they uncover processes that are 'relational and dynamic' (Clarke and Hoggett, 2009, p 13).

My initial approach to the use of researcher subjectivity was influenced by the work of Walkerdine *et al* (2001) who place greater emphasis on the emotional dynamic that is produced within interviews. They regard the experience of the 'defended researcher' as a 'primary instrument of enquiry' regarding the unconscious processes within the interview dynamic as a source of data in itself (p 84). Transference was originally a



concept developed by Freud, who found that patients unconsciously transferred emotionally-significant relationships onto their therapists. It can, however, also be understood in relation to a transference of emotions or feelings from one individual to another. Counter-transference can refer to an analyst's unconscious response to the patient or to significant people in the patient's life or to the patient's transference (Walkerdine *et al*, 2001). Although imported from the clinical setting, Walkerdine *et al* (2001) argue that these unconscious processes occur just as powerfully in a research setting as they do in any other interaction. By examining the thoughts and feelings felt by the researcher during and after the interview, it is possible to begin to understand and point to 'what might not (indeed cannot) be expressed by the subject' (p 90).

Walkerdine *et al* (2001) place significant emphasis on the creation of field notes following research interviews as a means of capturing some of the emotional dynamic as data. These field notes are not the same as ethnographic field notes, to build a more complete rich picture of the interview encounter; rather they are made to account for the unconscious dynamic between researchers and the researched. Appendix 4 outlines the framework I used to write my field notes following all 21 of my interview encounters with my participants. They were made shortly after the close of the interview, usually typed on the return journey from the participant's home. These field notes were partly descriptive, partly reflexive, and partly analytic, influenced by two key longitudinal studies that had developed a similar field-note framework (Thomson *et al*, 2011; Thomson 2010b; Henderson *et al*, 2007). Firstly, I would describe the process of access, setting up the interview, and any correspondence within this period. I would then describe the setting of the interview and the interviewee. Secondly, I would reflect on the emotional dynamic within the interview, describing my feelings, before, during and after the interview. Often, this would involve thick description and reflection on key moments within the interview, aspects of the interaction that felt unusual, difficult or

easy. At this stage I did not always understand what I had observed or was feeling. But it enabled me a point of reflection on material which in the interview may have been inaccessible because I was unconsciously engaged in dynamic processes (Walkerdine *et al*, 2001, p 93). My field notes helped me capture the layered nature of the interview and possible examples of the transfer of significant emotions or experiences.

While there are tensions with combining clinical (psychoanalytic) methods with longitudinal social research both entail a concern with 'duration' ('the demand to keep looking/talking over extended period of time') in which to analysis the individual and look beyond 'manifest meaning' (Thomson, 2010a p 16). Intensity is thus produced through this repetition of the research encounter, whereby psycho-dynamic layers of data can accrue and can be subsequently excavated. For example, gaps and inconsistencies or the repetition of emotional response over time can reveal the defences or desire present for researcher and researched. (Thomson, 2010a; McLeod and Thomson, 2009)

In the process of my research I became more closely attuned to the impact of the QLR framework and the impossibility of separating the researcher from the researched or 'stepping outside the temporal flow' of the research enterprise, from researcher's own biography to the fashions for different theories and models (Thomson *et al*, 2011, p 1). This recognition goes beyond the limited scope of the concept of the defended researcher (Hollway and Jefferson, 2013). While processes of hindsight and foresight can be mapped (more literally) in my participants' accounts of becoming a disabled mother through their reflections on past and present and imagining of the future, they also interact in the research process and can be accessed through researcher subjectivity. That is to say that the emotional responses and investments of the researcher and the way in which these change or repeat over time can provide insight into the experience

of research participants and the construction of social phenomena. I will return to this discussion in the next section.

### **Working with embodied difference**

The psycho-social element of my research design and method can be located in relation to a more recent call within disability studies for greater 'honesty' within the field and subsequent potential for 'collaboration' between disabled people and non-disabled researchers via reflexivity and an interrogation of dynamics within research encounters (Tregaskis and Goodley, 2006, p 365).

'... as researchers in applied disability studies we must begin to challenge at both theoretical and practical levels the commonsense assumption of a binary opposition that separates disabled and non-disabled people (Tregaskis, 2004a, 2004 b), and which thereby fails to recognise the relational nature of disablement, empowerment and interdependence in research and in life in general (Goodley, 2001).' (p 365).

Rather than view an interrogation of interpersonal dynamics as a means to 'empower' or improve our 'potential to conduct useful' (and ethical) research, I see psycho-social methodology as a further means of exploring the construction of disability in relation to my participant's experience, and that this process is a co-construction that occurs over a period of time (Tregaskis and Goodley, 2006, p 372).

Even before my research began I was conscious of a history within disability studies of a suspicion of non-disabled researchers of either the exploitation of disabled people for their own ends (academic credentials) or of contributing to the oppression of disabled people by reinforcing a personal tragedy model of disability (Oliver, 1997). The goal of 'emancipatory research' suggests that for disabled participants to experience power in

the research process non-disabled researchers must follow the research agenda set by disabled people, including the aims, methods and uses of the research. (Zarb, 1997, p 52; Oliver, 1992) While my research is not in this sense 'emancipatory' one of the benefits of using the FANI method was a limited interview schedule which enabled my participants to take the interview conversation into different directions, not necessarily reflecting my own conscious agenda (although obviously this process is complex related to the unconscious emotions in the interview setting). While my participants were not involved in the research design or (academic) analysis I was careful to feed back my initial interpretations at the end of my final interview as will be discussed in the next section.

Early feminist research also addressed the similarities of experience between female researcher and participant through their shared gender, enabling a positive establishment of rapport, a balancing of power relations and greater access to the 'truth' (Stanley and Wise, 1983). This argument, rooted in a realist epistemology, has been largely recognised as naïve within feminist studies not least because it ignores other aspects of difference and similarity within the research encounter, such as race or social class, which could have an implicit influence on power relationships within the interview. Others have pointed to the process of shifting power dynamics over the course of the research where participants are not 'victims', but both powerful and powerless at different points. Similarly, interviewers can find themselves feeling powerless and powerful for example the process of access in comparison to the process of representation in writing (Skeggs, 1997; Phoenix, 1994).

The dismissal of non-disabled experience neglects the relational nature of research and the fact that human existence is fragile, that we are all vulnerable, in need of some form of care, and subject to unconscious fears or desire (Phoenix, 1994). Rapport and

participation can build on a number of different factors that are not simply reducible to essentialist categories. Phoenix (1994) refers to the possibilities of shifting similarities and differences within research settings and hence shifting sympathies that are greatly amplified in a longitudinal project. She argues that, while aspects of difference such as race and gender and the power differences they entail enter into the research situation, they do not do so in a unitary way. As a result, the process of matching interviewers with participants is futile. Ultimately, what is needed is recognition that all knowledge produced in interview dynamics is 'situated', that is to say that all knowledge is 'partial' and linked to the context in which it is created (Haraway, 1991).

One way in which this process is made more explicit is through reflexivity, a process that magnifies the way in which difference shapes the research process. Feminists have come up with creative ways of enabling processes of reflexivity within their work. Rice (2009), for example built a project of 'embodied reflexivity' by combining a 'rooting' in one's own situation (one's position and history) with a shifting to the position of others through creative processes of imagining. Rice argues that 'for researchers from positions of bodily privilege, issues of interviewing and interpretation intensify when researching across physical differences distorted by oppressive cultural representations and social relations' (p 258). As a result, some bodily issues can be difficult to discuss or raise with participants. Attention to her own situation and shifting to the other enabled a recognition of her own 'body secrets' and potential ways in which this may shut down avenues of analysis or shape the project (p 255). This experience was also temporally defined where Rice's own biographical experience of embodiment differed from the body her participants interacted with in the present.

Rice's work is a classic example of how psycho-social approaches can inform disability studies. There has been a resistance in disability studies to the incorporation of psycho-

social methods to research design or any consideration of researcher subjectivity and the research encounter as a site of co-production of meaning, indeed the inclusion of personal experience (of disabled researchers) in research has been regarded as 'sentimental biography' (Barnes, 1997). Tregaskis and Goodley (2006) highlight the danger of becoming preoccupied with emotional effects or 'internalised oppression' as it can result in a neglect of the way 'psychical formations can give rise to ontological expertise about the conditions of disablement' (p 367). By reflecting on and taking seriously my own emotions and experience of embodiment through my field notes, I was able to explore more complex processes of the way in which difference was being experienced and made sense of in the relationship between participant and researcher.

### **How is it psycho-social?**

Throughout the course of my study, I disseminated my work-in-progress at conferences, seminars and workshops (see Hadfield, 2010a, 2008a, b & c). One of my aims was to develop further understanding of the defences of others in relation to disability by presenting my own subjective experiences in the research (the emotional dynamic) alongside my participants' accounts. I saw audience questions, feedback and a general observation of the group dynamics as a form (albeit a slightly intimidating and exposing version) of group reflection or analysis. Unanimously, throughout this process, my audiences focused on whether clinical concepts and methods could be transferred to the research setting. For some, my work represented what one conference participant referred to as a 'dangerous turn' in social studies towards the use of methods designed for clinical practice. The implication being that methods or concepts designed to help individuals are, at best, out of place in research setting and, at worse, seeking to capture a quality of depth that could cause psychological harm to participants. This is perhaps not surprising since my PhD research took place in a particular historical moment

within the academy characterised by a fierce debate about the applicability of clinical concepts and methods to social research (Baraitser, 2008b; Frosh and Baraitser, 2008). Frosh and Baraitser (2008) argue that attempts at engaging with the unconscious over a short period of time, in the uncontained research setting, and the mistaken assumption that colleagues can successfully interrogate the researcher's unconscious is futile (p 362-363). Indeed, in my discomfort with the FANI method, I found myself making comparisons with therapeutic practice, realising that any attempt to replicate the latter would be misguided. In therapeutic practice the analytical space is bounded by time and spatial context with professional and ethical safeguards that allow for a high degree of containment. In therapeutic practice the relationship between therapist and patient, unlike the research relationship (at least in relation to narrative interviewing), is ultimately created on the basis of reciprocity and inter-subjective exchange, which can take place over a long duration. In addition, the encounter is designed to help the patient, as opposed to benefit the researcher. If it is impossible to replicate the same conditions for investigating unconscious processes it is important to question whether psycho-social research methods can reveal instances for example of transference or counter transference. Frosh and Baraitser argue:

‘Psychoanalysis has more to offer when it’s disruptive and performative elements are placed in the foreground, that is when the kind of reflexivity it advances is one that acknowledges the way the phenomena of the psychosocial are produced through the actions of the analyst and analysand, researcher and researched. This means that cherished psychoanalytic ideas have to be rethought for the different context of investigation and expression.’ (p 363)

Baraitser questions whether it would be more apt to consider a different type of conceptual language drawing on Laplanche’s distinction between ‘psychological’ and

'analytical' transference (Laplanche, 1999; Baraitser, 2008b, 423-427). That is not to let go of the 'psychic reality' of a research encounter, but to treat it differently to a consultation.

Clarke and Hoggett (2009) have also questioned the applicability of psychoanalysis to social research. They argue that psychic 'processes' do not even need to be understood in relation to the 'defended subject'; rather projective identification, the way in which participant or researcher may be 'nudged' into taking a particular position in relation to the other, can be examined in relation to discourse subject positions. There is a parallel interest in clinical practice where 'both analyst and patient take up different positions in the micro discourse of an analytic session with who is speaking to whom, with what voice, and from what position' (p 13).

Crucially, what is significant in this debate is the solution offered by Baraitser to define the emotional dynamic or unconscious processes in a way that does not draw on the language of psychotherapy or fit to psychoanalytic theories. Or indeed to utilise the emotional dynamic not as evidence of particular 'psychic processes', but rather to make strange or 'rework the knowledge bases that we come with' (Baraitser, 2008b, p 426).

My research method clearly reflects this sentiment, and - where possible - I have attempted to describe what could be regarded as psychic processes in layman terms rather than rely on psycho-dynamic language without letting go of the premise on which the concepts are based. The problem with this approach, as I debated with my supervisors in the process of writing and analysis, is that without the use of psycho-dynamic or psychoanalytic terminology and theory, it is difficult to locate my research in relation to an authoritative body of work.



## **Ethical responsibility**

Returning to the conference participant's comment about the dangers of clinical methods, I was aware of the dangers of exploiting or misleading my participants or the potential harm of opening up sensitive issues for debate at a particularly vulnerable time in my participants' lives. The intensity and depth created by psycho-social QL methods raises dangers of invading the privacy of both participant and researcher. There is no easy solution to this dilemma (Thomson, 2007).

I made myself accountable to potential harm or exploitation by being relatively open about my interest in the emotions generated within the interview and through an ongoing process of consent (see Appendix 5 & 6 for my consent forms and information sheets). I also put supportive procedures in place for cases in which I suspected the participant or child was at risk of harm (see Appendix 7 for my account of ethical considerations). Yet, as will become apparent in the following four chapters, the construction of disabled parenting in policy discourse and related practice had a particular bearing on the way both myself and my participants made sense of their need for (emotional and practical) support. The procedures I put in place show some sense of foresight about potential fears about professional intervention. Despite these safeguards, however, I had not fully considered the impact of participant and researcher defences against being perceived/constructed as not 'coping' and the implications for access to support (see discussion of Magda's case study in Chapter 5)

With the right kind of external (supervisory) support, however, it can be argued that a QL psycho-social methodology can enable an interrogation of related defences or similar emotions on the part of researcher and participant. Consequently, it is possible that the intensive depth created by psycho-social methods can actually attune the researcher to a more sensitive approach to ethical issues of privacy and harm in a way

that may be overlooked in qualitative research that relies on data generated in one interview encounter. Rather than a focus on 'harm', it is possible to look to ways in which an analysis of emotional data could lead to positive and supportive intervention (where necessary) to benefit the emotional wellbeing, and even safety, of participant and/or researcher with implications for ethical guidelines and ethical practice surrounding research with vulnerable groups.

Intensive methods also raise further issues in relation to confidentiality and the representation of data, whereby the more data that is gathered about participant and researcher the more exposed and identifiable they become (Thomson, 2007). This process is as difficult for researcher as for participant who, working with a reflexive method, is by design exposing more of their private self in public dissemination than is usually given in traditional social research (see also Elliott, 2011). While, in the main, I found the process a stimulating and productive exercise, which appeared to open up frank debate among audiences, response was not always positive; I did on occasion feel more of a personal attack, due to the revealing nature of sharing subjective processes. Again, such potential vulnerability poses questions for the availability of support for researchers to work in this manner.

In the process of my research, I was also careful to discuss with my participants implications of dissemination. For example, in the case of Lizzie, she repeatedly asked me about whether I would write a book containing my participants' accounts; I explained the difficulty of participants becoming easily identifiable. For Lizzie, this cost was outweighed by the objective to take part in the study, which was to raise awareness and 'help' other women. Such an example demonstrates the way in which concepts of harm, confidentiality and anonymity or invasion of privacy are always context-specific and consent should always be re-negotiated on a case-by-case basis.

### **Section 3: A psycho-social longitudinal method of analysis and presentation**

In this section, I will outline my approach to the analysis of QLR data and the way in which I attempted to translate my findings into my writing. This process was by far the most complex and challenging aspect of working with QLR data, related to the management of the wealth and depth of data and the open-ended nature of longitudinal analysis.

#### **The analysis of emotional data**

One of the most challenging aspects of my analytical strategy related to my desire to work with emotional data alongside my participants' accounts. In my initial research proposal written in 2004, I naively assumed that I would be able to recruit a team of academics or students who would be prepared to read my reflexive field notes and encourage me to reflect on aspects of the emotional dynamic I was perhaps more defended against. In reality, this form of group analysis did not take place. Such a group would have demanded a regular commitment and time with little rewards for the participants. Neither did I have access to a trained psychotherapist, as has been the case in other empirical psycho-social research projects (Elliott *et al*, 2011; Walkerdine *et al*, 2001). This restriction again highlights the validity of Frosh and Baraitster's claim that social research cannot lay the same claims to analytic reflexivity as the clinical method. Despite these limitations, I developed significant resources in which to develop this reflexive space drawing on my supervisory team and opportunities to share my field note data and interrogate my interpretation of the emotional dynamic through my participation in psycho-social groups and networks. These reflections have been included in my analysis and the writing process.

In the process of my research, however, I came to realise that the real value of combining a psycho-social approach with a longitudinal research design was the space

that is afforded to analyse the layered nature of the interview dynamic. The passage of time not only gave me the opportunity to reflect on what may not have been accessible in the past but I found myself able to reflect on my data from different positions or 'vantage points' (McLeod and Thomson, 2009; Walkerdine *et al*, 2001). The seven-year framework of my study (with an additional year of maternity leave) saw significant changes in my own biographical position: from a desire to answer my own questions about disability and difference to a recognition of the importance of motherhood as a source of difference and connection. My own experience of infertility and motherhood inevitably produced different perspectives for my analysis of the data at different points in the research process. Due to the opportunist nature of my sample the research process itself enabled a building of insight across cases, by which I mean that I went to interviews with participants with the knowledge and insight built from previous participant encounters, inevitably leading to comparisons or rather 'conversations' across cases and a 'multiplicity of vantage points' (McLeod and Thomson, 2009). These insights have been woven into my analysis and will be revealed in the following chapters. For example by interviewing Cathy who became a mother through surrogacy as I first embarked on my fieldwork I became more attuned to the way in which my other participants in contrast afforded less time in their narrative to the discussion of their visibly-pregnant body (as will be discussed further in the next chapter).

As McLeod and Thomson (2009) argue, the researcher remains the living connection between the initial fieldwork encounter and the moment the data is revisited. Emotions can be seen as providing the link between the different temporal narratives that are contained within the research process, including biographical time (of both researcher and researched), research time (the timetable of the research process), analytical time (the process of analysis and writing) (Thomson and Holland, 2003). Accordingly, reflections written at different stages in the analytic process enable a more 'recursive

temporality' (McLeod and Thomson, 2009). This recursive process begins with the initial field note, which McLeod and Thomson (2009) argue should always be referred to in its rawest form to avoid fantasies about the past associated with the here and now in the present. In Figure 3, I have presented the different stages of my analysis to document the way in which this process was mapped over the course of the project. As can be seen opportunity for reflection on the data (including the emotional dynamic) are made at different stages in the research process, I have also given an approximate indication of the dates in which these processes occurred to give a sense of the passage of research time.

**Figure 3: Process of analysis**

|   |
|---|
| 1) Interview Preparation: Gathering key info and themes via screening questionnaire and access (2005- 2006)   |
| 2) Wave 1 Interview: Attention to themes, phrases and emotional dynamic. (2005-2006)  |
| 3) Field-note Reflections: Made immediately after interview.  |
| 4) Opportunities for Group Reflection: Interrogation of emotional dynamic and researcher subjectivity. Attention to emotional dynamic within group and own feelings afterwards. (Ideally occurred shortly after interview in supervision)                               |
| 5) Transcription of Wave 1 Interview and further field-note reflections: A) Attention to themes, phrases and emotional dynamic in interview. B) Attention to emotional response on listening to the interview, anything missed/alternative interpretations? (2005-2006) |
| 6) Interview Preparation: Gathering themes as above to weave into interview questions/reflections on change. (2006-2007)  |
| 7) Points 2-6 repeated for Wave 2 & 3 Interview   |
| 8) End of Case -Wave 3 Interview: Feeding back of themes and opportunity for participant to reflect (2007-2009)   |
| 9) Writing of Case Profile for Waves 1- 3 interviews (2009)   |
| 10) Cross-cutting analysis of key themes across cases   |
| 11) Mapping of continuity and change across and within case (2009-2010)   |
| 12) Writing of three data chapters arranged according to temporal phase. Writing of whole thesis. (2010-2013 with one year maternity leave in 2011)   |

By making the presence of hindsight and foresight explicit in my analysis (taking into account the multiple vantage points) I found myself able to develop what Thomson and Holland (2003) refer to as a 'provisional and mobile' understanding of my data (p 243). Examples of hindsight and foresight were mapped at different stages from my questions, hopes and fears for my participants in my field-notes to the moments of realisation captured at the point of transcription (where further notes were made), analysis of my data and in the process of writing. By reflecting on an emotional dynamic in the past from a different vantage point I began to recognise that I was involved in a 'continued search for intelligibility' through my unique connection with my fieldwork data (McLeod and Thomson, 2009, p 164). Moreover, this search was not carried out alone due to the relationship between researcher and participant. While I was engaging with my data at different points in the analytical process my participants were also on their own journey of discovery, attempting to make sense of their situation all the while engaged (if only partially) in documenting this through the research process. It is this two-way relationship that signifies the co-production of meaning or simultaneous projects of sense making, evidence of which was particularly felt in my participants' enthusiastic and engaged responses to my feeding back of reflections at the end of the final interview.

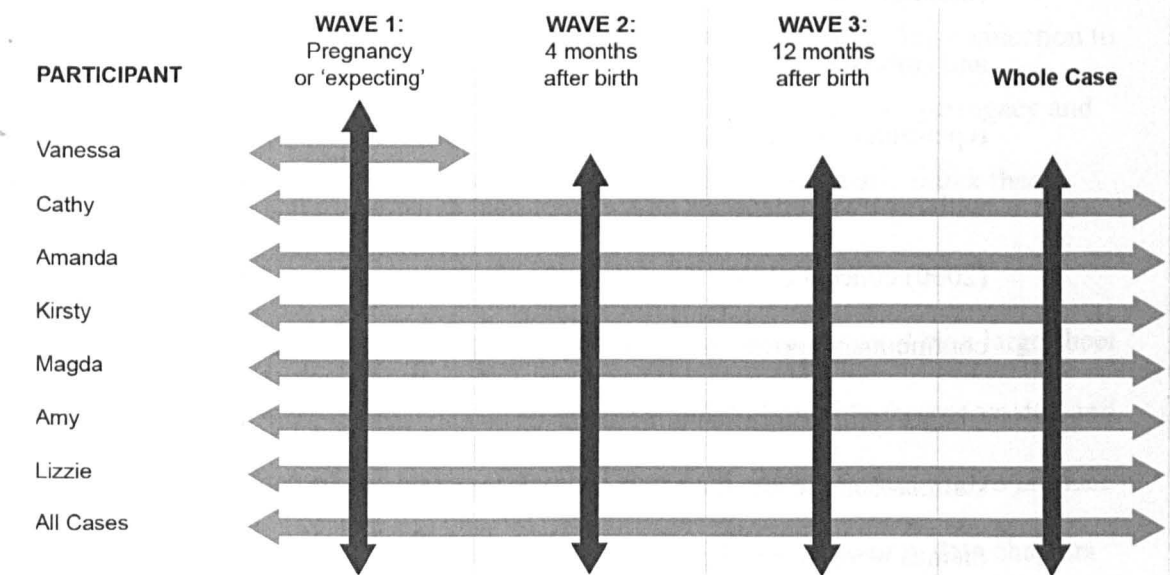
This analytical process, aided by field notes and reflexive writing, can offer one way of managing the multiple vantage points afforded by QLR and retain a certain element of distance and objectivity that is necessary the organisation and presentation of my research findings. There are, of course, limitations to this sense of distance. While the passing of time and changes in circumstances can enable a reflection on what may not have been possible to be seen at the time - for example, due to the researcher's own defences around her own 'disability' or infertility - some of these defences may be too deeply felt to be revealed over the course of the research process. There is also always

the problem with longitudinal research that the analytical process is never quite over even when the fieldwork is long since finished. I will return to this point later in this thesis.

### Mapping biographical journeys

I turn now to the final stage of organising my analysis and procedures for writing; focusing on stages 9-12 of Figure 3. My aim in my analysis and writing was to produce insight through placing different pieces of data in conversation with each other. Such a juxtaposition of data can be through elements or temporal moments within one individual's biography or case history/archive or across different cases at the same temporal moment. These directions of analysis have been termed diachronic (longitudinal) and synchronic (cross-sectional) retrospectively (Thomson and Holland, 2003). The direction of these analytical processes can be seen in Figure 4 below.

**Figure 4: Directions of analysis**



Returning to Figure 3, I began in stage 9 by producing a written case profile or case history which, reflecting the temporal structure of the data for a single case was organised in relation to waves of data collection. Case profiles were designed to

condense primary data from a case data archive (the detail in the collection of individual transcripts). This process is not simply a documentary method; rather, the purpose is to carve out an 'analytical story' or history of the case containing 'specificity, concrete events, juxtapositions and coincidences' (Thomson, 2007, p 9). My case profiles were predominantly descriptive, allowing space for the particularities of my participants' situation and accounts over time to be drawn out, going beyond the limitations of thematic frameworks that reduce accounts to a series of codes or nodes. Where possible I used participants' own words and highlight these in italics and speech marks. In addition, I would also include my own field-note data and any subsequent contemporaneous reflections and wonderings about my own subjective responses. In doing so, it is possible to preserve and integrate aspects of the emotional dynamic within the research encounter, and capture as much as possible of the participant's voice (Thomson, 2010a). Working within case histories, I mapped processes of sense making (intelligibility) as narrated and emotional paying attention to the intermeshed emotional and embodied effects of these processes (Thomas, 2007). I did this through attention to repetition of key phrases, motifs and emotions within my participants' accounts together with my own reflections on the emotional dynamic. In this process, I found Saldana's (2000) concept of the 'through line' a useful way of short-handing themes that continuously appear within and across my participants' case histories, while foregrounding significant moments or turning points. Moving on to stage 10, I summarised the key themes from each case for each of the interviews. These key themes were then mapped out for each participant for each wave of data collection, allowing themes to be measured against or talk to one another as a form of cross-cutting analysis. While my longitudinal direction of analysis evaluates accounts over time, mapping transition, change and continuity my cross sectional analysis identified evidence of socio-cultural constructions of disabled bodies and the way in which



women were making sense of these constructions in a particular temporal moment (Thomson, 2007; Kirkman *et al*, 2001).

Moving on, I was faced with the challenge of both mapping and presenting my findings into a coherent narrative. It was this process that proved the most challenging. Despite the condensation of my participants' case histories into a series of thematic codes at both the descriptive and conceptual level, I still found it difficult to let go of the detail in my participants' interview accounts. I decided that the only way of retaining the complexity of my participants' longitudinal accounts was to map their journeys temporally, mirroring the linear framework of the research design and their transition from expectancy to motherhood, as can be seen in Figure 3. In this sense, my participants' experiences are drawn in conversation not around conceptual themes (such as autonomy or visibility), but through a focus on key moments - that is the embodied, life-course and relational aspects of my participants' experiences in the transition to motherhood. In doing so, I am able to contrast those moments that formed significant turning points for some participants such as conception or birth, enabling connection to be made in relation to other aspects of difference, (such as social class, surrogacy and experience of impairment) and drawing on my conceptual framework to link these patterns to wider social processes.

Practically, this process involved drawing out the processes in Figure 4 on a large sheet of paper and marking key moments, turning points and highlighting themes, motifs and quotes from my participants' accounts and my own field notes. My aim was to produce a clear temporal account across all the cases from which to structure my data chapters which would trace through lines across case histories, highlight key moments and turning points in a way that would visually cluster together around common and contrasting experiences. Admittedly, I found this mapping method deeply unsatisfactory due to my conflicting desire for a clear map while balancing the specificity and detail of

my participant's particular situation (as a means of accounting for similarity and difference across cases). In addition, it became increasingly frustrating as, due to the nature of longitudinal analysis, I found myself adding layers of understanding and insight over time, meaning that I had to redraw and edit the paper. Others have also highlighted the weaknesses of cross-sectional approaches that divide up chunks of data according to the theme or codes related to difficulties maintaining the integrity of individual accounts and making the research process apparent in the data (Thomson, 2007). As mentioned before this process is characteristic of longitudinal research as others have argued 'analysis and data collection are never finished; interpretation is always provisional' (McLeod and Thomson, 2009, p 78; McLeod, 2003).

Following my process of mapping and analysis I was faced with the difficult task of organizing my data for the three data chapters. The difficulty I faced again related to my desire to show the depth of individual cases that I feared could be lost through presenting my cross-cutting analysis. After experimenting with different ways of presenting my data I chose to organise my chapters in relation to the temporal sequencing of the research process. In doing so I hoped to retain elements of the different journeys over (biographical and research) time. Chapter 4 is concerned with my participants' accounts told while expecting and the experience of the research encounter; Chapter 5 is concerned with the period approximately four months after birth; and Chapter 6 is one year to 18 months after birth. The presentation of cross-cutting key moments within these accounts invites the reader to engage with common or contrasting events or encounters, while holding onto the unfolding of individual processes of meaning making over time. My own reflections and those of my participants, made in relation to hindsight and foresight, add to this process preventing the emergent picture from becoming too linear. Recognising that this process could mean that the 'through lines' of individual cases are lost, I have included a vignette in

each chapter which has a relationship with the theme of in/visibility (Salandia, 2003). Each vignette has been selected to illustrate the importance of the wave or interview encounter as a temporal moment in which the complexity of 'in/visibility' is revealed. In my first draft of the data chapters I divided my chapters by focusing first on the cross-cutting data, returning to my vignette at the end as a means of illustrating depth. As I redrafted my chapters, however, I became more confident about weaving the vignette into the story of the chapter where my discussion of cross-cutting themes gives way temporarily to a longitudinal story.

In sum the process of analysis and writing has been long and complex. To add to this my own biographical journey entailed a year maternity leave, meaning that the process felt more drawn out and layered. I hope, however, that the following three chapters have captured some of the depth of my data while also providing a clear story of my participants' experiences and our co-constructed processes of making sense of disability and motherhood.

## **Conclusion**

In this chapter, I have continued to map my research journey from my research design and methodology to my approach to analysis and writing. In the process, I have reflected on some of the methodological questions and issues that arose in the duration of the study. I have attempted to show how I negotiated epistemological, ethical and practical issues at each stage of the process and how these questions and dilemmas shaped my research design and method. These issues will be returned to in Chapter 7. In the next three chapters, I will illustrate how this data has produced key insights in relation to the experience and understanding of disability in the transition to motherhood. Processes of intelligibility play a key feature in the production of identity for six of my participants over the course of the first year of motherhood. I begin in the

next chapter with my participants' experiences of 'expecting' either through surrogacy and adoption or pregnancy.

## Chapter 4

### Expecting

In this chapter, I begin to map the series of journeys into disabled motherhood. I will present aspects of all six of my participants' accounts of their journey so far, at the point of expecting their first child through pregnancy or surrogacy and adoption (details of my sample can be found in Table 1, in the previous chapter). In addition, I will capture the emotional dynamic through my descriptions of my encounters with the pregnant or expectant body. The central motif across my participants' accounts over the following three data chapters is that of in/visibility. I start the chapter from this point, drawing out my position as a curious observer and the way in which the in/visibility of the pregnant and/or impaired body engineered a series of challenges about the meaning and significance of difference for our understandings of disability and disabled motherhood.

My intention in this presentation is to highlight the way in which pregnancy and/or the anticipation of motherhood acts as a significant turning point or embodied 'epiphany' in my participants' biographies with the potential to de-stabilise, disrupt or confirm the way in which they have come to make sense of their embodied experience as disabled women (Warren and Brewis, 2004, p 221).

I begin my presentation in Section 1 with my participants' reflections on their lives before conception, highlighting autonomous and gendered body projects. In Section 2, I move on to my participants' accounts of conception and pregnancy including the absence or limited discussion of the visibly-pregnant body in public space. This absence is particularly significant in the context of a common culture of motherhood that apparently celebrates the visible bump (Thomson *et al*, 2011; Tyler, 2008). I then move on to specifically map aspects of Cathy's account from this point of 'expecting' through surrogacy to one year after birth. Cathy's case has been selected for this chapter to

illustrate how the juxtaposition of invisible expectant motherhood with visible disability creates tension which speaks back to what appears to be unsayable in my other participants' accounts. I end my presentation of my participants' accounts in Section 3, highlighting their imaginings of the future, drawing out their preparations for birth and motherhood and reflections on available support and resources. Finally, I will conclude the chapter, returning to the emotional dynamic as I ended my interviews with all six participants including any challenges present in leaving and my hopes and fears for the future.

### **Introduction to the emotional dynamic**

My first encounters with the participants in my study highlighted important questions about the significance and nature of embodied difference. Before these first encounters I felt incredibly nervous, related to the issue of researching across lines of difference. I found myself worrying about how my interest in their situation would be received as a visibly-able-bodied person. Would my fascination with their bodily experience be regarded as intrusive and perverse or as a welcomed interest?

My preparations also revealed an awareness of the authority of medical definitions in relation to my participants' experiences. Quite unlike my previous experience of preparing for interviews in other research projects, I described in my field notes my attempts to visualise my participants' bodies and digest their descriptions of disability (given on their questionnaires and initial correspondence) as I travelled by train to meet them. Both Kirsty and Magda drove to pick me up from the station and I noted how I watched them make their way from the car to meet me; their limited mobility, impairment and bump becoming more visible. My field notes revealed a preoccupation with the impaired body;

‘I say that I suddenly realised on the phone that I wouldn’t recognise her but obviously I would. She laughs and says yes look for the pregnant person but I had in my mind the fact that she would be walking with a crutch.’

This preoccupation gave way to confusion. In our first meeting, I was for example taken aback when Amanda opened the door of her flat to welcome me, as she was barely shy of my own five-foot frame. Despite the obvious visible markers of a growth condition our similarity in relation to height was a striking presence throughout our first interview. I reflected in my field notes on my discomfort as Amanda referred to her similarity with other ‘short’ women (including myself) in the interview, whether these comparisons could really be made and how I should respond to them.

These first encounters also became sites of more direct challenges and confrontations. I “often wrote of a more conscious desire not to engage with my participants’ impairments; mirroring the social model framework. As became apparent, however, this get out clause did not relate to my participants’ perceptions of the significance of their impairment for our encounter, or indeed their experiences. In my field-note reflections following my interview with Lizzie for example, I described the way she thrust her medical notes upon me shortly after I got through the door to ‘prove’ that she is disabled (related to her assumption her arthritis is invisible) and my caution in providing the ‘right’ response. Before the interview had even begun Kirsty lifted her trousers to show me her splint and the way that her foot was curled, something that I described in my field notes as making me feel both curious and uncomfortable. I soon began to acknowledge my lack of resources in empathising with her situation but also the limited discursive space that is available for non-disabled people in this regard. Reflecting on these encounters in my field notes I found myself questioning my own professional status, where I seemed to occupy a curiously observant position.

At other moments, however, I found myself beginning to identify with and admire my participants, highlighting the way in which the experience of disability intersects with other elements of difference and commonality. Magda appeared to invite identification, drawing on a shared experience of conventional normative heterosexuality and body size. I note how she reflected on our similarity in height and we discussed the limitations of being short in reference to our wedding dresses (a conversation sparked by the display of her wedding photo). I also found in the 20-minute journey to and from her home to the station that I had revealed considerably more about what I felt at the time was my own 'ambivalence' for motherhood than I had intended, wanting to get the PhD done first.

My encounter with Lizzie, however, revealed more challenging emotions in relation to the temporality of difference and the possibilities (even for healthy and attractive middle-class women) for loss. In my initial correspondence with Lizzie she included a link to her website which included snippets of her music and photographs of her dressed in various vintage outfits (a hobby). My notes in my research diary before our first interview described these photographs. I also questioned my capacity for creativity in my own work and my curiosity about Lizzie and how she had made this a priority. On our first meeting I was struck by Lizzie's attractive appearance. She was dressed in a long flowing multi coloured vintage kaftan that disguised her small bump, with thick long black hair. Yet despite her confident and articulate manner, I described the way her small frame appeared 'engulfed' by her friend's dark flat, in which she had come to live in temporarily after leaving her abusive partner. This juxtaposition of what had first appeared to me as cultural and embodied wealth with her invisible experience of disability, homelessness and relative poverty, served to create a troubling emotional dynamic within the interview as will be revealed at the end of this chapter.



My participants settled on their sofas, Lizzie swamped by a dark leather couch, Cathy on a steel dining chair with her computer glaring behind her and Magda sat at her handmade oak dining table drinking tea. In most cases we were alone. Interruptions were marked in my interview with Amy, by the new technology that had been given to her in pregnancy to alert her to the doorbell and telephone. Partners were not present except for Kirsty's husband who worked from home and came in and sat in on the interview at different points, interjecting with his own version of (shared) events. Amanda set the timeframe of the interview explaining that in 50 minutes she would be meeting her husband for lunch. For the other participants, however, the interview appeared to be a welcomed time for reflection on the past and present and imagining of the future.

### **Section 1: Reflections on the past**

In this section, I will focus on my participants' reflections on the past as they introduced their journey into disabled motherhood. I will introduce the way in which they present their experience of autonomy and dependence, in relation to past encounters with medical professionals, parents and peers; with implications for their perceptions of difference from others and linked experiences of in/visibility. It is here I learnt of the body projects my participants begin to construct in relation to negotiations of medical diagnosis and social and embodied autonomy. My participants' accounts have been divided to contrast the experiences of those who grew up as disabled girls and those who became disabled in their mid-20s.

#### **Growing up disabled**

Cathy, Amanda and Amy's respective accounts about their experiences of disability began with birth. All experienced different levels of visibility related to their impairments, aids and equipment. Cathy was born with a congenital heart defect,

Amanda was born with a rare growth condition and Amy was born deaf. Magda's account began in early childhood when she developed a brain tumour age three. Both Magda and Cathy underwent surgery in childhood (age 3) that resulted in impairment. For Magda the surgery resulted in the loss of use of her right hand, she also walks with a small gait and has a curvature of the spine. Cathy has prominent scarring across her chest and the surgery she received as a child also caused a stroke which resulted in the loss of use of her left hand and paralysis down her left side. Amy had a cochlear implant which was fitted in early childhood. While Cathy used a wheelchair after recent surgery (a couple of years before the interview) she, Amanda and Magda had not used aids or equipment throughout their lives.

### **Autonomy and integration**

The accounts of early childhood provided by Cathy, Amanda, Magda and Amy inevitably involved encounters with medical professionals and for Amanda the social services that would continue into her late teens. Cathy and Amanda both described the way in which their childhood was punctuated by moments of feeling different as they were 'poked and prodded' by medical professionals because of the rareness of their conditions as Cathy explained.

'I was REALLY just sort of left to get on with it, to be honest. I used to have to go up to \*City twice a year to be poked and prodded and (.) passed round. Because there's not a lot of people with my condition. So I think I was a bit of an oddity, (laughs) probably still am, yeah.'

In Amy's case the decision of her local education authority to integrate all deaf children into mainstream schooling meant that her parents had 'no choice' but to consent to the fitting of a cochlear implant.

‘Everyone had to speak and not use sign language so erm it was (.) not forced on my parents but they didn’t really have any choice but to let me have hearing aids to learn to speak. I had to go to a mainstream school. Which was quite difficult because I was the only deaf person in the school. I was very much the only person which definitely had an impact on my life and the way I saw myself as a deaf person.’

Integration into society with their non-disabled peers became key to these participants’ early experiences of disability, their understandings of their capacity for autonomy and their perceived difference from others. Cathy, Amy and Magda gave descriptions of integration which focused on the determination of their mothers to enable their autonomy. Amy’s mother spent considerable time, giving up her job to stay at home teaching her to speak and lip read with the implant; so that she would be able to get by at school. My participants also gave accounts of the way in which their mothers either resisted, or accepted authoritative knowledge, about their daughter’s capacity to integrate into society as disabled individuals.

Magda’s mother played a significant role in ensuring that Magda had what she described as a ‘normal’ childhood and not to be treated differently from others.

Resisting medical advice;

‘She refused to send me to a specialist school because she knew there was nothing wrong with my brain.’

Magda told me with affectionate laughter of times as a child when her mother would encourage her to engage with ‘flospy’ (her hand) and to walk and move about. This activity seemingly defied medical authority, which had declared that following the operation; she would never walk or talk (as a result of brain damage). While the medical profession left Cathy to ‘get on with it’ in relation to coping with her impairment, her

mother refused to let a social worker in the house as she could 'look after her own child'.

Amanda's mother on the other hand gave her up at birth. Amanda did not give me a reason for this and neither did I ask as it felt a painful question. My assumption was, based on Amanda's explanation that she was not 'expected to survive' that her abandonment was related to the unexpected discovery of her growth disorder.

'I am not a hundred per cent sure what the circumstances were, why I was put in foster care but I know I was very ill as a baby. And obviously 35 years ago they didn't have scans so I am assuming that really they didn't know an awful lot about what was wrong I was sort of in special care for about six months because I was sort of small, my lungs were not developed. ... .. I don't think they expected me to survive from what I have kind of picked up.'

Reading her case files as a young adult was so upsetting for Amanda that she ended up having a 'panic attack'; learning how she was passed around different foster parents until eventually given a home with her foster family. Following the death of her foster father when Amanda was a child, she described her foster mother as falling into a 'depressive state' something Amanda links to her negative perception of Amanda's growth disorder.

Amanda's account of her (foster) mother's parenting did not capture the promotion of autonomy and equality that others spoke of. Rather, Amanda was sent 'confusing' messages about her place within society as similar to and different from others. While she was expected to 'get on with things like everyone else' at school and home she was also continually told by her foster mother that she would 'not be able to achieve things like other people', and in particular that she would be unable to 'carry a child'. Despite

these claims Amanda explained she was never given any information on her growth disorder and the reason it marked her out as different from others.

‘I was always told that I couldn’t do things that other people couldn’t do, I was never, I was never given a real reason for that... .... It does have an effect on you ... .. I have a lot of fears of things. I think that is inbred from constantly you having different expectations of you than other people.’

Amanda’s social environment (at school and home) made no allowances for her physical limitations and offered no emotional support for her experience of being a foster child.

### **Belonging and difference**

For Amanda, Amy, Cathy and Magda the early experiences of engaging with concepts of autonomy had implications for their understanding of themselves as different in their interactions with others. Cathy and Magda presented ambivalent accounts about their identifications with other disabled people. Both refer to themselves as disabled, both emphasised their ‘normal’ upbringing and schooling as a means of marking themselves out as different from other disabled children. Cathy’s rejection of the groups for disabled children her mother encouraged her to attend as a child extended into her rejection (with her visually impaired husband) of formal support groups as an adult:

Cathy: But there weren’t any other disabled kids in my school that I can remember, (laughs) you know... .. my Mum sort of said, “Oh you must - you should go to some clubs and things like that,” but I’ve never felt like (.) it’s - I don’t think it works. You know, I don’t think to go to something where people always all have (.) a particular disability in common means you’re actually gonna find anything else in common with them, you know, that you’re

actually gonna make friends with people. Because I'd go to these things and I never really felt like (.) it really did anything for me. ... .. I probably spend more time (laughs) NOW with disabled people than I ever have, (laughs) you know. But we're - we're NOT the sort of disabled person who goes to groups that are for disabled (laughs) people. You know, I kind of just tend to go out and do what I wanna do.'

In Magda's case, however, there was little interaction with other disabled people (other than her brother who has learning difficulties) as she asserted:

'I didn't see myself as any different because this (my impairment) was just normal to me, I didn't know any different. I didn't know any disabled people. There was some bullying but it was more to do with me being a small person than being disabled...'

Amanda described feeling confused about the significance of her growth disorder and questioned how she was different from other 'short' children:

'I would look at them and think well they are small but are they like me, why can't I do what they do? I didn't really consider what I looked like...

She described the way she dealt with her confusion as a child, relating her capacity for integration, autonomy and even survival in embodied terms (being loud):

'I was a feisty child, quite angry. I realised that I had to be loud because small, quiet people get bullied.'

Amanda described a key moment as a teenager when she began to question her identity in relation to embodied difference:

I remember at once I saw a guy and he had dwarfism obviously so he did look physically different to me. I remember feeling really shocked. Sort of, just by

seeing him really thinking oh is that what I am like because I was told very little growing up. You know I didn't understand ...it was just complete and utter confusion really. It is this whole thing of thinking well who am I? And then you have got the added issue of sort of thinking well you don't even know where you came from. It was a very, it is very odd really, yeah.'

A significant turning point occurred in Amanda's early adulthood in relation to her identification with other people with her condition when she attended a conference for people with similar growth disorders. She describes this moment as a revelation:

'Walking into that room and seeing people that looked like me... .... (but) were confident and happy in themselves... .... it was like coming home.'

Despite this sense of 'belonging' Amanda's confusion about herself in relation to others continued well into adulthood and her sense of 'anger' about the way she had been treated, resulted in a considerable period of time in counselling.

Amy articulated a greater certainty of her difference from others in childhood. In her own family, she felt the 'odd one out', unable to understand her father's thick accent when he spoke and resented by her brother for the extra attention she received. Amy also described the difficulty of being in groups at school and not being able to follow conversations through lip reading and being marked out as different as she was taken from classes for coaching by her 'teacher for the deaf.' Despite moving to different schools with better deaf awareness, it was when she became a teenager and joined youth clubs for deaf young people who sign (an older generation who had not been subject to the Local Education Authority approach to integration) that she claims a feeling of belonging:

' I found out that (.) it was normal (.) to feel (.) everything I was feeling, feeling frustrated about not understanding people and what I was going through at school they were going through ... .. I don't know what I would have done if I had not found out about that group. I would have carried on being really frustrated and isolated I think (.) so (.) it really did help me a lot. And we went through a lot together as we got older erm, because there becomes a point where everyone I spoke to says the same thing, there comes a point where you just get cross about the fact that you are deaf. '

Within her account Amy articulated this as a turning point, from feeling different to belonging. In her late teens, however, she explained that disillusionment with her deaf peers and their apparently self-destructive behaviour ('all they wanted to do was get drunk') meant she began to look to other areas for this sense of belonging and acceptance. Joining the church in her late teens gave her an inner sense of 'peace' that she struggled to articulate.

'I realised I was a Christian first and foremost and then Amy and then, the deaf person.... I guess before I just didn't feel ... valued... Being deaf is just a part of me. It doesn't define who I am now'

Therefore, in all four cases, it was clear that in childhood the process of working out who they were, highlighted key questions about the significance of their embodied experience (impairment) in relation to identification with disabled and able-bodied others. These processes ranged from denial and confusion to a sense of understanding and acceptance.



### ***Gendered bodies: growing up as a disabled girl***

Adolescence served as an important time in the identification with their (non-disabled) peers related to a questioning of their capacity for sexual autonomy and the desirability of their disabled body. As a child Amanda could play 'boisterously' and run about with the other children. She described the changes in her body as a teenager as particularly difficult as her body remained childlike in stature even though she began to grow breasts. Similarly, Cathy described her adolescence as 'bloody terrible really' and described herself as physically 'gawky' and her awkward attempts to cover her (heart surgery) scar, limiting her ability to wear skimpy tops.

Relationships with the opposite sex also marked them out as different from their peers. Magda explained that it was not until the boys 'began to run in the opposite direction' from her that she became more aware of her bodily difference from her peers. Cathy recounted a particularly painful memory of inviting an able-bodied friend along to the PHAB (short for physically handicapped and able-bodied) youth club and then watching as she 'proceeded to get off with' the boy she fancied.

Perceptions of their bodies and in particular the visibility of their impairments became central to their accounts of establishing romantic relationships. Cathy and Magda both recalled their sense of amazement when men confirmed they found them attractive.

After meeting her partner online Magda questioned:

'what did you expect before you met me, did you see my hand, did you think I would be in a wheelchair?'

### **Autonomy, education and work**

For Cathy, Amy and Magda education and career became key markers of their capacity for autonomy and success alongside their able-bodied peers:

As Cathy explained:

‘I just had the idea that disabled people get discriminated against when it comes to jobs so I thought right what I need to do is get an education.’

All three recalled important moments in their educational progress in which their career choice was challenged due to perceptions of their capacity for embodied autonomy with their impairment. Amy was advised particularly by her ‘teacher of the deaf’ that English literature would be a better choice of degree than physiotherapy on the basis of her grades. But I also got the sense that Amy believed that the practical aspect of physiotherapy played a part in this advice:

‘I thought well I will apply for Biology as that is more generic and they can’t argue against that.’

Her success in achieving a physiotherapy degree and a career in physiotherapy was accounted for in almost fatalist terms:

‘But I thought I have got to do physio that is what I want to do. Why can’t I just do it? I was always destined to be a physio because that is what I have always wanted to do... .... Looking back I can see why people did think I can’t do it. But, it has been difficult, it has not been without its problems, I have had support anyway so it has been fine.’

Magda was advised to switch her physics course to biology because of a perceived physical inability to carry out experiments she pursued what she called a ‘normal’ education finally achieving a Master’s degree in history. Cathy was advised by her careers advisor against a course in childcare or a career in nursery nursing because her impairment would get in the way of her capacity to lift and care for children.

‘I was really upset about it. I felt that there was nothing I could do. Because you know possibly, possibly what they were saying was true actually. You know maybe I wouldn’t have coped, I don’t know. You know obviously some things I couldn’t have done. Yeah I don’t know. I suppose it is different with other people’s children. (laughs) Put me in charge of somebody else’s child.’

Both Magda and Cathy pursued careers they felt were compatible with their impairments, Magda eventually settled on an administrative role in a university. Cathy initially trained as a careers advisor before changing course and finally becoming a youth worker. In Amanda’s case, education and a professional career (as a youth worker) were combined with the experience of living independently in her late teens.

‘I never really wanted children. I always quite liked having my career and being able to sort of do what I wanted really. And also being an independent person.’

### **Synchronisation and motherhood**

- For Magda a determined pursuit of a career was also closely related to her perception of her limited chances of meeting a partner or her ability to conceive:

‘Part of me felt I will never meet someone who will want to have a family with me or we didn’t know what problems there could be so I just channelled my mind through education. And career rather than being a mother.’

Both Cathy and Amanda spoke of a key moment in their late adolescence in which a medical encounter transformed their perception of their ability to become a mother. Amanda had assumed since she was a child that she would be unable to have children because of her growth condition. In her final meeting with her paediatric doctor Amanda asked if her condition would limit her ability to have children and was told it would not. His response evoked a mixture of emotions for Amanda where she felt both

pleased and angry. Her anger in particular is linked to her sense that others (namely medical professionals and her foster mother) felt she had no rights to knowledge about her own body:

‘That was a real revelation for me. I thought oh my god nobody had told me this before. ... Because I thought it is okay for everyone else to have the right information but because it was me it is not important.’

Similarly, for Cathy, aged 15, an encounter with her heart consultant was an intensely negative experience in which she was advised that if she ever were to fall pregnant she should come to her for an abortion because of the perceived dangers of women with heart conditions carrying children. Cathy links this key moment to her sense of ownership over her own body.

‘She said if you ever get yourself in trouble come to me you know for an abortion. And I was like; you know it was the last thing on my mind, god look at me who would have me. ....but I did feel quite upset.. They think they know absolutely everything, and they are God, and you just do as you’re told, and you should be grateful that you’re alive. You know, and SHE did my surgery and said - (laughs) I suppose she thinks she’s got the right to tell me what to do.’

These encounters with medical professionals in their late teens reveal a key shift in my participants’ understandings of their capacity for sexual and reproductive autonomy, seemingly disrupting their sense of themselves as similar or different to their able-bodied peers. It is a moment that can be contrasted with the relative agency afforded in their determined pursuit of integration and equality through education and work.

I turn now to the experiences of Lizzie and Kirsty who became disabled in adulthood. Both recount similar themes related to the loss of embodied autonomy and the questioning and acceptance of embodied difference.

### **Becoming disabled in adulthood: Lizzie**

Lizzie has severe psoriatic arthritis, which developed in her early 20s, although she suffered early symptoms of 'psoriasis' (a skin condition) as a young child and teenager. Lizzie's arthritis mainly affects her spine, hip joints and neck. In pregnancy, with the exception of Lizzie's psoriasis her arthritis was relatively invisible. She lived in constant pain despite the prescription of pain relieving drugs and her mobility was limited and she made occasional use of a mobility scooter.

### **Losing embodied autonomy and seeking medical assistance**

Lizzie's account of becoming disabled was complex and closely entwined with her visible psoriasis and her own fertility. As a child she was bullied for her skin condition and had been hospitalised as a result of the bullying. In addition, her skin condition meant that she was marked out as different through medical monitoring and observation.

'I had this terrible skin which you know looked awful and really made me stand out.'

As a teenager, Lizzie found greater acceptance for her skin condition from her peers; in young adulthood, however, she chose to invest in a project of improving her skin through a course of alternative treatment from a herbalist. Unknowingly this involved an illegal Chinese herbal medicine which causes temporary ovarian failure and can lead to false diagnosis of early menopause. The intensive hormone treatment and medical

intervention involved in the process of diagnosis resulted in debilitating periods which left her housebound. Lizzie described this as her 'first taste of what disability was like'.

Emotionally Lizzie had to come to terms with the mistaken belief that she would not be able to have children which included a period of counselling. It was only after three years that Lizzie's diagnosis was proven to be false at which time she began to feel aches and pains in her spine. It was eighteen months later, during which Lizzie was not given appropriate pain relief that she was finally referred to a rheumatologist who immediately diagnosed her with psoriatic arthritis. This final diagnosis was a 'huge relief, to be believed rather than fobbed off'.

Lizzie's account revealed a struggle with her sense of agency and control over her body. Her agency was proven to 'backfire on (her) big time' as in an attempt to improve her skin independently of medical intervention she seemingly put herself (both bodily and emotionally) through a stressful chain of events. This is all the more pertinent in relation to Lizzie's understanding that her condition (psoriasis) is closely related to stress. It was only with appropriate medical diagnosis that Lizzie was able to get support for her arthritis.

### *Accepting embodied difference and downward social mobility*

Becoming disabled in adult life signalled a particular turning point in Lizzie's life trajectory. Lizzie began her account by asserting her particular middle-class background, explicitly and repeatedly describing herself as 'middle class', highlighting her educational success and career.

'Right. My parents are (.) well I would put them as (.) lower middle-class. ... ..  
... so that is kind of where I am in society. Well that is where my parents were,  
erm. (...)'

Lizzie did well in education and after gaining a degree she began a career as a lecturer at a university. It was at the stage in her career when she began her first full-time post that she was diagnosed with ovarian failure.

Lizzie narrated this experience of presumed infertility and latterly the development of her arthritis as incompatible with the male dominated sector of academia in which she worked. She felt unable to make these invisible aspects of her embodied and emotional experience visible:

‘For starters I had enough wrong with my body already with the psoriasis... you begin to feel like a freak and you really just want to be treated like everyone else.’

As her arthritis developed Lizzie found it difficult to get up on a morning and had to take a lot of time off work. Following her period in counselling Lizzie began to open up to her colleagues about her disability but found that the invisibility of her condition meant that she was misrecognised as ‘lazy’. In addition, she felt that many of her colleagues were ‘embarrassed’ by her condition.

‘Providing my psoriasis is covered up I look perfectly well and I look brown all the time, I look very healthy so people just assume that you are swinging the lead.’

The onset of her arthritis marked the ‘end of (her) career’. Without ‘sympathy or support’ at work Lizzie handed in her resignation and returned part-time only to discover that she had the same workload. Eventually when a permanent contract came up Lizzie failed to get it. Lizzie found potential employers unwilling to accept and work with her limitations, inquiring as to whether she will be able to do open days and other such activities outside her contracted hours. She explained how it begun a downwards

spiral in which her relationship with her partner at the time suffered. The breakdown of the relationship meant that Lizzie had to give up her share in their joint property.

Lizzie's account of becoming disabled is thus closely associated with downward social mobility, something she appeared to resist. For example thrust into the world of benefit assessment Lizzie described the way her status as a 'middle-class person' acted against her as she was expected to fill in forms for disability living allowance without assistance in the Citizen's Advice Bureau.

'I found myself really in a big trap in terms of being really a middle-class person. I didn't seem to get a lot of help as other people would....because I told her about being educated she just handed me the forms and basically told me to go away (laughs).'

Reasserting her family background as middle-class and the centrality of work and career to her family's outlook, she described the way in which her parents were particularly unsupportive in relation to her arthritis. Lizzie described an unsuccessful six months where she tried to engage her mother with her experience of disability following which she moved out of her mother's home:

'She is the sort of person that thinks by sheer willpower you can beat arthritis, and you know if only I tried harder I would be able to get another job.'

Like Amanda and Amy, Lizzie found comfort during this period by drawing on the support of other women in a similar situation. Lizzie drew on an American arthritis website and related forum.

'I have asked (my mother) to read it sometime to get a handle on how other people are with the same illness. She just says that she found it really negative and really depressing. But I, one word for that mother, DENIAL. ....there is



humour and comradely and great strength in knowing you are not the only one whose got these problems.'

At this time Lizzie had begun a relationship with her childhood sweetheart and made the decision to move in with him based on the fact that she was without a job or home. This relationship served to contribute further to Lizzie's sense of downwards social mobility and eventual isolation as it became abusive. While she was initially wary of his 'manipulative' behaviour she found herself giving him a chance rather than 'sorting out my job or rescuing my career'

### ***Becoming disabled in adulthood: Kirsty***

Kirsty's experience of disability also developed in her early 20s while training in London for a specialist aspect of her degree. She fell over and damaged her sympathetic nerve running between two buildings at work. Following the accident which resulted in her impairment and limited use of her left leg Kirsty experienced a long process of testing which eventually resulted in a diagnosis for 'Reflex Sympathetic Dystrophy' or 'Complex Regional Pain Syndrome'. After Kirsty's accident she spent time in a wheelchair before attending a specialist physiotherapy unit where she learnt to walk with crutches and eventually with a splint or on the side of her foot.

The defining theme of Kirsty's account about her early relationship with medical professionals like Lizzie's was that of neglect. After her accident she was treated for a sprained ankle and told to return to work. While her consultant increased the dosage of her medication, Kirsty claimed he failed to take seriously her complaints about her experience of pain and her sense of dis-attachment with her leg, both of which she later discovered were symptomatic of her disorder, 'He just wouldn't believe anything I had to say. I wanted my leg amputated.'

Together with the constant pain she endured, and the sickness induced by the high levels of medication Kirsty described her appointments with her GP as like 'hitting a brick wall.' When a private consultant diagnosed Kirsty's condition it left her in;

'Disbelief... it is not easy knowing that this is going to be forever.'

The emotional weight of the diagnosis caused Kirsty to 'self-harm' over a period of time. With the support of her GP who referred her to further physiotherapy and counselling Kirsty was able to come to the realisation that amputation would not solve her issues with her leg as the 'pain pathways would still be in place'. While she still 'hates it with a vengeance', it enabled her to come to terms with her diagnosis and understand her disassociation with her leg as symptomatic of her condition. Counselling helped Kirsty make sense of the emotional impact of becoming disabled particularly in relation to self-harm:

'It was a cry for help.. not true self harm, there was no intention behind it, it was just me trying to get people to listen to the fact that I needed help, I needed some people to support me.'

Like Lizzie, Kirsty's account revealed a struggle with her own sense of agency and control over her body. For Kirsty the real struggle was in relation to her leg and the wish for it to be removed. Logically Kirsty assumed that the removal of her leg would end her experience of pain. Not only was her agency denied (she was unable to convince the medical professionals to remove her leg) but she had to come to terms with the irrational logic that her desire to detach herself from her leg is all part of her condition.

Like Lizzie, Kirsty begun her account by asserting their particular middle-class background, as 'never wanting for anything'. Kirsty was particularly single minded in

her pursuit of a career, following to the letter the recommendations of a computer programme that assessed her suitability for certain professions. After gaining a degree in Speech and Language Therapy it was while training for her specialism that she had her accident. Kirsty's account of downwards social mobility was less explicit than Lizzie's. Kirsty was signed off work as on long time sick leave and spent a significant time house bound. She was eventually able to resume her employment with support from her employers and medication. Unlike Lizzie, Kirsty had the support of her parents, particularly her mother who was also disabled and used a wheelchair and was able to empathise with Kirsty's experience. It was in Kirsty's account of the period immediately after her accident that she revealed frustration at her seemingly diminished social status. Public interaction with her impaired body and that of her mother's highlighted for Kirsty her perceived infantilisation:

'When you are in a wheelchair my IQ drops by at least 30 points'.. she said, 'Oh have you got sneezums too?' And it was like she has got three degree and I got one. Why do you feel that you have to speak to me like I was six?'

This perceived slight on her IQ, counters Kirsty's account of educational and career success, reduced in one moment to a child who cannot speak for herself. Unlike Lizzie, however, Kirsty appeared unable to relate to or identify with other disabled people on disability forums and had resisted joining disability groups;

'They just seem to have it far worse than me ... .... I do see myself as disabled on some level but when I do I tend to get quite angry with it and quite, if I see it as something I have got to get over I can see it as something that can be accomplished.'

## **Gendered bodies: becoming a disabled woman**

While education and career were key to Kirsty's account of success, reflected in her class background of never going without, she also envisaged a couple relationship and motherhood:

'It was always part of my plan, I was going to go to university, get a career, get married and have babies all by the time I was 30. I am going to be two months off by the end of it so (laughs).'

Kirsty decided to make the 'proactive' decision to join an internet dating site after the death of her mother in her late 20s. Hidden by the virtual space of the internet Kirsty was faced with the question of revealing her impairment and status as a disabled individual. Initially, Kirsty received 'quite a lot of interest' from men based on her photograph and without any mention of her 'disability or problems' on her introduction sheet. She found, however, that once she revealed her impairment it would cause difficulties in her interactions

'One of them just turned around and said that in an e-mail that he wasn't interested in taking someone on with a disability.... .... It was really kind of hard to know when to write it in. It is part of me it is obviously something you have to know but it is not who I am or what my brain is like or anything else.'

Meeting her partner Steve, was recalled in terms of her big 'plan' where 'for me that person has to be part of the decision making process.' It is at this point that Kirsty appears to reassert a more determined account. While she was unable to express what exactly about Steve 'caught (her) eye' she found him at a moment when due to the other comments she was 'about to throw in the towel... I'd just have to go through life alone.' While slightly alarmed by the speed at which the relationship developed ('a bit scary')

she explained the couple are 'very, very close', marrying shortly after they met and spending little time apart.

Lizzie and Kirsty's accounts highlight how becoming disabled in adulthood entails a stark disruption in the taken for granted experiences of (abled) autonomous bodies. Both precariously balance a desire for medical recognition with the loss of embodied independence and social autonomy. Moreover, their accounts powerfully demonstrate the intersection of the classed and gendered experience, through the immediacy of lost hopes. This speaks back to the accounts of Cathy, Magda and Amy for whom the intersection of class and gender are present but less explicitly voiced.

By contrasting my participants' accounts in this way it is possible to see patterns of gaining and regaining social and embodied autonomy in their 'body projects' and the acceptance of loss (Shilling, 1993; Featherstone, 1991). Inherent to this process is an ongoing conversation or challenge in locating experience of (visible and invisible) difference in relation to others both disabled and non-disabled. All of my participants appeared to draw on a sense of what some articulate as 'determination' or a 'feisty' nature to present the way in which they negotiated challenges and moments when their capacity for autonomous agency and the successful synchronisation of education, career, and relationship success is disrupted in their biographical accounts.

## **Section 2: Conception, pregnancy and the present**

In this section, I will focus on my participants' reflections on the more immediate past as they introduce their experiences of trying to conceive, conception and pregnancy. As I have discussed in the previous three chapters, synchronicity of biographies and a sense of choice are key features of the common culture of motherhood, marking the right time biographically for women to become mothers (Thomson *et al*, 2011). I begin by focusing on the subject of fertility, highlighting the moment of conception as an

important time in my participants' relationship with their bodies in which their embodied autonomy is confirmed.

### **Autonomous fertile bodies**

With the exception of Lizzie, all of my participants made careful plans to become pregnant with their partners. While Amy was a relatively young first-time mother at the age of 26 the others were all over the age of 30. For some, fears about their capacity to conceive in relation to their impairment intersected with fears of leaving it too late and knowledge of potential fertility problems (for Kirsty, Magda and Amanda). In these cases anxiety about their capacity to conceive led to consultation with medical professionals and in some case medical assistance and intervention. Magda began her conception account by asserting her own ambivalence about motherhood:

'He is the kind of person who goes up to buggies whereas I run away from them...I am a bit yes-no.'

When feared symptoms of an early menopause occurred, however, Magda became panicked that she had left it too late, resulting in the need for medical testing. In addition, Magda embarked on a private, independent and intense 'body project' including internet research to maximise her chances of conceiving each month alongside (home) ovulation and pregnancy testing, echoing her mother's childhood efforts to defy medical knowledge and intervention. This period, however, also marked a particular shift in which, in contrast to her childhood experience (of relative independence from medical professionals), Magda invited a new relationship with her GP based on monitoring and medical surveillance.

'My doctor is absolutely brilliant, he has a daughter who had a brain tumour like mine, she unfortunately died but he asked me lots of questions that help other

people and he has just been really interested . Erm and there has never been,- because he used to sort me out when I had cystitis and he said, I said to him you have probably got my own seat in the waiting room, and he said no no, it is fine we need to sort this out for you.'

### **Balancing autonomy with medical authority**

Magda's example, however, highlights a potential tension between claiming medical assistance in the context of biographical accounts that have highlighted autonomy and determination. It marked the beginning of what appeared to be a paternalistic relationship with her GP whom she claimed was particularly interested in supporting her because his own daughter shares the same condition. Magda turned to her GP to support her belief that she will be unable to look after a disabled child. He supported her decision to undergo a further amniocentesis test if the initial screening test for Downs Syndrome at her 12-week scan suggested high risk and supported her preparations for the possibility of a termination. Faced with her husband's disapproval and dismissal of the need for such measures Magda described how her GP had explained to her husband how difficult she would find mothering a disabled child:

'He did say, you know knowing Magda's problems and knowing how much help she needs you know I think you will find it very difficult with a Downs Syndrome baby ... .... it is not going to be good for you it is going to be too much. And Neil kind of understood and said, yeah I understand now.'

While Magda's account highlights this encounter as supportive and reassuring there is the danger that by drawing her GP in to make observations about Magda's physical limitations she is inviting assessment of her capacity to parent.

The tension between medical assistance and embodied autonomy was also present in Cathy's account, although it played out with quite different results. Cathy explained that part of her determination to become a mother was based on the negative encounter with her first heart consultant about her ability to conceive and carry a child.

'I have always wanted to be a mum, I knew I wanted to be a mum before I met Ian but I also KNEW because of a heart consultant I had when I was younger. ...'  
(goes on to recount the encounter detailed earlier in this chapter)

Cathy went on to describe how she was able to combine this determination with the progressive views of her second heart consultant in adulthood who advised that open heart surgery would give her the best chance for a successful and safe pregnancy.

'I had open heart surgery, (laughs) you know, which is a very big deal. But (.) I think most people were thinking, "Mad." But I was thinking, "I wanna do it," so (.) I did.'

While Cathy was able to conceive she experienced an early miscarriage. Following her miscarriage she resolutely gave up her job to maximise her chances of conception and carrying her child to term with limited stress: 'I thought right this time I am going to do it properly'. Sadly Cathy's second experience of conception resulted in her son dying at 23 weeks' gestation.

The couple's loss entailed an end to Cathy's pursuit of embodied autonomy with medical assistance. It was not, however, an end to Cathy's 'determination' to prove her first consultant wrong and become a mother. Choosing to abandon natural conception as a route to parenthood the couple looked to an alternative 'body project' in surrogacy. This surrogacy arrangement was set up by a national organisation who matched 'hosts' with married couples. The couple had been warned that they would have less success with



IVF using Cathy's egg so decided to go ahead with a 'straight surrogacy' using a combination of her partner's sperm with the surrogate's egg. Cathy's account of the surrogacy arrangement documents a number of ways in which Cathy (together with her husband and the surrogate) balanced embodied dependency with a sense of autonomy and control while 'expecting'. This balancing act was one aspect of the complex interdependent relationship between the surrogate, Cathy and her husband. Cathy's orientation to the surrogate's pregnancy mirrored her unsuccessful pregnancy, where the couple decide not to discover the sex or screen for downs syndrome.

'Because we didn't find out when I was pregnant with Charlie, and I thought, well I don't - I want it to be the same, you know.'

In addition, I learnt in our final interview of the way the surrogate had also emphasised the importance of making a ritual out of the conception process passing a cup of sperm through Cathy's hands before she made the insemination and offering Cathy a pregnancy test as a keepsake.

'She said I would like it if Ian brought the sample back downstairs and then handed it to you and then you handed it to me. And I said okay, I mean I wasn't bothered if I was involved or not.'

As I will explore later in this section, however, the nature of embodied dependency on a third party that surrogacy entails held particular challenges for the way in which Cathy related to her eligibility as a disabled mother.

### **Medical control and resistance**

As discussed in the previous section, Lizzie's experience of disability was closely entwined with her experience of assumed infertility. She described infertility as an invisible and private experience, akin to her experience of having arthritis. While the

discovery of conception is privately celebrated by Lizzie her encounter with her G.P mirrors the negativity others (Cathy and Amanda) experienced in adolescence:

‘He assumed that I wanted an abortion. What? No this is very much a wanted baby. He was like, you want to keep it? YEAH?!! Course I do... .... made me feel pretty disgusted. Like some doctors think you need to be sterilised as a matter of routine. You are not up to scratch, you are a reject... ....’

The complex way in which medical professionals can both enable embodied autonomy and subject women to dependency and/or surveillance is demonstrated in relation to pain relief. For Lizzie pregnancy marked conflict with her GP and rheumatologist over her access to pain relieving drugs: where her drugs were withdrawn on the basis of benefits to the child’s health:

‘A lot of the doctors seem to treat you like King Herod when you are pregnant .... You should grin and bear it...for the sake of your baby’.

Rather than accept her status as property of the medical authority (sterilised as a matter of routine) or as deviant/immoral (refusing to put her child’s needs above her own)

Lizzie embarked on independent research with significant results:

‘I was saying I have read in the British National forum that this medicine is safe until up to 30 weeks of pregnancy and said well I would like to keep taking it because I am in a lot of pain, I can’t do anything and I actually do need some form of exercise....Didn’t do anything. ... .... eventually the obstetrician ended up prescribing a very low dosage ... .... (otherwise) I don’t think I would have been able to get out of that relationship. So, god bless Prednisone because it has been absolutely fantastic.’

In relation to fertility, conception and pregnancy, I have shown how my participants balanced medical advice with their own medical research and in Magda's case the use of specialist ovulation strips bought online. This practice mirrors to a certain extent the common culture of motherhood in which women are encouraged to draw on different sources of expert (medical) advice in the monitoring of their pregnancy (Thomson *et al*, 2011). This agency, however, occurs in the context of perceived negative attitudes of medical professionals in relation to embodied or social autonomy (the distinction is not made). As a result, there is the danger that my participants carefully managed biographical accounts of determination, autonomy and successful integration are rendered fragile and even absolute. While Cathy was able to incorporate her encounter with her consultant as a teenager into her 'determined' account of becoming a mother Magda's experience warns of the potential implications of these attitudes, when women are vulnerable or anxious.

### **Wonderment, achievement and challenges**

The moment of discovering the conception was recalled by all as that of surprise, shock and wonderment. For Magda a sense of pride and amazement is articulated in relation to able-bodied others who are unable to conceive as quickly and efficiently.

'I work, you know we just didn't know if I would have problems conceiving and I just thought, in that word, NORMAL! (laugh) ..Other women it takes them such a long time'

The surprise and wonder these participants recount is not only specific to disabled mothers. As research has shown surprise and wonderment is common for all mothers but particularly older mothers and for those who previously experienced fertility problems (Thomson *et al*, 2011). What is significant, however, is the way in which my participants made sense of this experience of fertility in relation to their position as

disabled mothers. I was struck by the way that Kirsty, Magda, Lizzie and Amanda all made reference to the fertility of their own bodies in relation to the infertility of able-bodied others. For Lizzie this comparison was particularly pertinent in relation to her own (assumed) experience of infertility before her arthritis developed. She explained:

‘I am absolutely staggered by the way my body has changed and how efficient it has been in pregnancy. I have probably found it much easier to cope with the annoying side of being pregnant than a lot of women because my daily experience of being in my body is imperfect anyway and annoying.... ..  
The feeling of having a baby move inside you is pretty miraculous.’

Conception for Kirsty marked another defining moment in her relationship with her body in which it defied her expectation. While the couple had anticipated conception taking some time due to her diagnosis of Polycystic Ovaries they conceived relatively quickly. Kirsty compared her sense of shock to her previous experience of coming to terms with her impaired body:

‘Something nice has happened but you are still just as shocked as when there was something bad happening.’

### **Strange embodiment and apprehension**

For Kirsty, pregnancy marked a strange embodied experience in which she struggled to link her experience of impairment and the possibilities for pregnancy. Kirsty described a preoccupation with the experience of her baby moving which could be felt in her leg causing a sense of confusion:

‘I mean my head tells me that the baby has to be moving in my stomach, in my tummy area because that is what makes sense I know I haven’t got a baby growing in my leg.’

These accounts echo the confusion and process of coming to terms with her experience of disability in early adulthood. Similarly, Amanda's account of her pregnant embodiment focused on her growth condition and her fears that she would be unable to contain the growing foetus.

'Am I going to go into labour early because the baby is going to fill up all the space in my stomach?'

Mirroring her childhood experience of confusion and not receiving the right information, Amanda struggled with the acceptance of medical knowledge to the contrary. In particular, her fears about passing on her condition to her child overwhelmed her as his growth was monitored. Despite medical reassurance Amanda felt unable to let go of her fears that she would be unable to carry the child or that she would pass on her growth disorder despite the fact she had been told it was a recessive condition.

'There is always that fear at the back of your mind, of course, there is...you do worry every time.'

While as I have shown Amanda's account of her pre-pregnancy self is feisty and angry, able to look at other 'short' bodies and assert her own physical and mental resilience, her embodied experience of pregnancy with a growth condition revealed her vulnerability.

'Physically not being able to see your feet ...if they knock someone really tall then they will be okay ...it is not just you, you are carrying sort of the baby.'

The experience of in/fertility had significant implications for my participants' interactions with medical professionals, demanding a re-engagement with and a revisiting of medical control and autonomy. This moment marks an intensification of

the visibility of their bodies in relation to medical expertise. Their accounts express a sense of pleasure but with this a feeling of heightened vulnerability and confusion. This has implications for the kind of support my participants drew on in the present and imagine in the future, something I return to in the next section.

### **The in/visibility of the bump**

In their accounts of encounters with others the bump either appeared to be hidden in public interactions, or made my participants feel more conspicuous as was the case for Amy:

‘I hate people staring at me. I think it is natural for me to feel like that anyway... I want to be the same as everyone else. That definitely comes from being at school...I have to remind myself, it is all natural...actually it is not because I stand out for the wrong reason.’

For Kirsty having a visible bump meant a continual conversation about her impairment and how it interacted with her pregnancy in encounters with others, resulting in her and her husband retreating into the privacy of the couple relationship and the domestic space.

This private experience, however, says nothing of the common experience reported by (able-bodied) women of public interactions with the bump as a source of public property, subject to unwelcome comments and touch (Thomson *et al*, 2011). Indeed, I was struck by the limited discussion within my participants’ accounts of their experience of public interactions with the pregnant bump in contrast to their accounts of public encounters with their impaired bodies pre-pregnancy. To explore possible explanations for this absence I turn now to Cathy’s account of becoming a mother through surrogacy.

## **Encounters with the invisible bump: Cathy's case study**

As I have presented in this chapter, Cathy's particular body project involved the experience of an inter-dependent relationship with a surrogate. Cathy's experience can thus be contrasted with that of my other participants as she was confronted with the limits of her embodied autonomy at the stage of conception. Due to the legal background of surrogacy arrangements in the UK the legitimacy of her status as the unborn child's mother was not made until the baby was officially adopted some four months after birth (Hadfield 2008a; Johnson, 2003; Strathern 2003). As presented above Cathy also lost an earlier pregnancy at 23 weeks, and the intense emotions associated with this were apparent in our interview encounter. This complex situation highlights the intensity and fragility of Cathy's transition to motherhood in our first two encounters, particularly when considered in relation to dominant embodied cultural norms surrounding motherhood.

- In addition, the nature of surrogacy arrangements within the UK demands an element of public accountability (Hadfield, 2008a, b & c). The legality of the arrangement meant that the couple were routinely visited by court social workers and would need to attend court for the adoption of their child to be passed. Cathy and Ian made their surrogacy arrangement through an organisation that encouraged its members to publicise surrogacy as a positive experience. Cathy's involvement in my study and speaking on a local radio show was all part of this project to make surrogacy more 'acceptable' in the face of the 'bad news stories that hit the headlines'. This element of public accountability, however, also extends to Cathy's everyday public interactions in which she finds herself having to tell the conception account. She explained the telling of this account was met with mixed responses:

'you can just see it in their eyes that they're kind of thinking, (sniffs) not sure about that.'

In her accounts of these interactions Cathy described an argument with a male colleague who thought bringing a baby home would be like the 'surreal' experiences of adoption in the 1950s and the response of her elderly neighbour who reassured Cathy that she need not tell:

'She said, I would have just assumed you adopted, I didn't want to (.) I thought it would be a bit strange to just sort of suddenly appear one day.'

Cathy's description of a trip to the supermarket to buy a steriliser details the kind of assessment she felt herself subject to:

'She looked me up and down, "cos I was wearing like a short T-shirt, (laughs). And she said, "Oh you're hiding that well." I kind of leaned over and said, "Well actually....."'

Despite her openness, however, Cathy revealed the emotional work involved in presenting her expectant body, choosing not to attend any prenatal groups to meet other mothers admitting to feeling 'a bit self-conscious'. She explained

'Because (.) you do get judged by non-disabled people.. ... maybe if I was pregnant myself I'd be a bit more bold about it and like, "There's my bump, so sod off," you know. Well actually we're having a baby through surrogacy, and yes we're disabled as well," (laughs) I wouldn't feel comfy.'

Cathy's particular experience of visible impairment and her invisible route to motherhood through surrogacy generated a complicated emotional dynamic over our three encounters. In our first interview this was generated through the following direct appeal:



Cathy: 'But, you know, I don't know (.) and I suppose people don't (.) don't know really, people don't tend to notice. I mean I suppose it's pretty obvious I've had a stroke, I suppose, I don't know. What do you think? (laughs)

Interviewer: Not to me.

Cathy: Not to you? Well I've got no use of my left arm. But people don't tend to notice. And they don't know that I've got a heart condition a LOT of the time.

.... ..

Interviewer: So how does that make you feel, like me saying I didn't really, and people saying they don't really notice?

Cathy: Fine, I don't care, (laughs) you know. I mean I - I don't know, because I suppose if I'd (.) no I definitely prefer it'

In my field notes following my first interview with Cathy, I described an awkward moment in reference to this interview exchange:

'She started making facial expressions to get me to comment on this. I felt this had been coming for a while and physically recoiled.... wanting to hide behind my role as interviewer particularly in relation to the clinical background of the method. A therapist would probably bounce back the question asking her to reflect on it. But that felt dishonest and disrespectful. I instantly said no rationalising to myself that her impairment is not obvious... However, while it appeared to please her I wanted to backtrack. When she walked to the kitchen to make me tea (and her impairment became more visible) I realised all the more how ridiculous my response was. I didn't say anything else.'

This moment in the interview offers a glimpse into the emotional toll of Cathy's particular experience of her body as both disabled and as a recipient of surrogacy.

Rather than challenge Cathy, I took on a reassuring position, denying her bodily difference despite the fact that it inherently felt 'ridiculous.' Following this first interview with Cathy my fieldnotes document a sense of discomfort related to the part I played in denying Cathy's impaired body. Drawing on Goffman's concept of 'passing' I debated whether I was complicit in our interaction in enabling Cathy to present a 'false self' or deny her impairment to fit in with the 'normal' society (Goffman, 1968; Davis, 1961). Considering my reaction I questioned whether this interaction reflected Cathy's desire or was evidence of Cathy responding to some of my own emotional work or 'interest' (1968, p 65). By this I mean that perhaps Cathy realised that listening to (the hardship) her story as an able-bodied woman was difficult to bear.

In our second interview, our difference as mother and non-mother, coupled with my own unexpected desire for a child, created an altogether different dynamic in relation to Cathy's body. This encounter occurred four months after the birth of her daughter Jasmine. Sitting side by side on the sofa with Jasmine initially set before us on the floor and later in Cathy's arms my field notes reveal both my desire to reach out and lift Jasmine (which I did not do) and my observation at Cathy's physical awkwardness and lack of physical confidence.

'She shook her arm out in the direction of the baby who was on the floor and said, "This is Jasmine". I was slightly shocked it seemed a bit detached. ... ..  
... Jasmine's sock fell off. I put it back on before telling Cathy who told me there is no point they always fall off. She later told me that she hates people interfering or telling her what to do. ... .. Cathy proceeded to change Jasmine's nappy only to discover that her nappy did not need changing. I felt she was self-conscious with me watching.'

While my notes revealed detail of my conscious admiration of the way in which Cathy lifted and handled her daughter ('I was impressed... single handed'), it is also clear that Cathy and I were treading a delicate path with regards to Cathy's legitimate position as Jasmine's mother. My own maternal desire and Cathy's anticipation of being judged by professionals all served to complicate this dynamic. At this stage Cathy had not yet legally adopted Jasmine and the surrogate had retreated from making any contact with the couple. Aware of the potential insecurity of the arrangement I found myself again been drawn into a reassuring role in a discussion about both Cathy and Jasmine's bodies:

'Cathy said that the baby looks like her partner but sometimes people say the baby looks like her. In my head I was thinking about an incident when I was 16 at my grandmother's funeral. After the funeral distant relatives commented on how I resembled my (step) father. But I didn't tell her this and instead I said, "People do say the more time you spend with someone the more you resemble them". After I said this I realised that is what people say about dogs! Cathy said she might stop dying her hair so it looks like the baby's hair.'

My notes described the 'heavy depressed feeling' I took away from my second interview with Cathy. I reflected on my feeling that I had not done enough to reassure Cathy that she is doing a good job, my fears that 'I had missed signs of something akin to postnatal depression' and my inability to reassure her of my conviction she is Jasmine's mother: 'despite my conscious efforts to refer to Cathy as Mummy in my conversations with Jasmine which appeared to please her'. Again my role in enabling Cathy to 'pass' as Jasmine's mother albeit in the moment felt uncomfortable and questionable.

It was only in our final interview shortly after Jasmine's first birthday that I was able to let Cathy's continued reflections on her physical similarity with her daughter pass.

'I said, "She is gorgeous" - Cathy laughed and said, "Yes she is and I am taking the credit for that when I shouldn't really". I wanted to say no, I didn't mean the way she looks, rather how happy she is. But all I said was, "yes you can."

At this stage not only had Cathy gained legal status as Jasmine's adopted mother but she had also faced one of her fears, that of social service observation following an incident in a health clinic in which she dropped her daughter (this encounter will be returned to in the next chapter). Cathy's discussion of her sense of obligation to tell of how her daughter was conceived shifts from the responsibility to let her daughter 'know where she came from' and the pleasure involved in passing for her biological mother through their assumed physical resemblance. Reflecting back on her experience Cathy sums up her experience of being disabled and becoming a mother through surrogacy;

'You do get odd looks off people. I don't care I said that before. I can tell what people are thinking (talking too quietly for recorder) 'you have got a baby'.

Obviously they don't know the back account but that is why I don't want to tell people really. I am just glad that I am managing as well as I am. Because I think if I was struggling really badly then (.) well it would be terrible but I think also I would feel embarrassed and ashamed. Conscious I suppose of it. And maybe I would feel maybe I shouldn't have done this, maybe I shouldn't have had a baby. (.) But I don't feel that. Because in a way I feel quite proud of myself. You know because I am the sort of person who if I want to do something then I can. I will never quit. (baby noises, to baby) You all right darling? Yeah. I don't think that I should have to defend myself really to people. If they don't like it tough.'

The emotions I described in my field notes shortly after our last interview were that of pleasure and triumph as I state:

‘Such a relief, a feeling that finally I can write up a positive conclusion to Cathy’s story.’

Cathy’s case highlights the way in which the experience of embodied dependence in the form of surrogacy intersects with Cathy’s understanding of disability and disabled motherhood. Related to this is her understanding that both embodied situations entail abjection from cultural norms about reproductive bodies and motherhood. ‘As I have shown the motif of visibility is woven through this experience in complex ways. Central to the way she makes in/visibility intelligible is the repeated denial of difference. ‘Tough’ determination remains a key theme across her account as she asserts her position in encounters with others.

What is significant in the processes of emotional sense making across the vignette, however, is how my understanding of the work of ‘passing’ developed over time (Butler, 1993; Goffman, 1968; Davis, 1961). It was only following the third interview that I was able to understand that Cathy’s account of disabled motherhood was not about presenting a false self (attempting to pass as able-bodied or as a biological mother) neither was she denying her impaired body or her status as an adoptive mother to fit in with ‘normal society’. Rather the repeated temporary imagining in the interview encounter (through a denial or seeking embodied resemblance) or claims to dominant social norms (as able-bodied and a biological mother) that I am also complicit in, questions or ‘queer’ the significance of fixed categories of impairment, disability, and the natural biological mother (Butler, 1993). This process appears strange because of the limited cultural resources or language that are available to challenge the way in

which disabled maternal bodies are constructed and the intense emotional connection she feels with her daughter.

Her performance is, however, one that occurs within the distinct space of the interview encounter, in marked contrast with the way in which Cathy makes herself accountable to her experience of surrogacy and prepares herself for discrimination as a disabled mother. It is as I have illustrated an intensely emotional process of sense making revealing the fragility of her processes of sense making behind her 'tough determination'. Therefore, such performance highlights the disempowered and fetishized role of the marginalised and abjected subject and the limited resources that are available for the deconstruction of norms in everyday life (Butler, 1993).

It is significant that while Cathy fantasises about presenting her 'bump so sod off', as I have highlighted for the rest of the sample reflections on public interactions with the bump were either limited, over -looked in relation to the experience of impairment in pregnancy, or absent. This on the one hand can be accounted for as a result of the 'forbidden gaze' where others avoid engaging with the visibly-fertile disabled body (Williams, 1997). Indeed, returning to the emotional dynamic at the outset of our meetings, it is clear that I found it difficult to engage with both aspects of embodied difference by focusing predominantly on impairment. Yet Cathy's account demonstrates the emotional work involved in encounters with visible and invisible difference and the maintenance of a 'tough', determined outlook. While the artistic representation of disabled maternal bodies can be seen as provoking or challenging our perceptions of embodied experience, the lived experience of such embodiment in everyday encounters (both real and imagined) is understandably difficult (Betterton, 2009). When combined with the emotional and embodied challenges in the transition to motherhood, the sense

of vulnerability and hopes and fears for the future it is not surprising that a focus on encounters with the pregnant bump is markedly absent within my data set.

### **Section 3: Imagining the future**

In the previous section, I showed how for many of my participants the experience of pregnancy entailed a process of revisiting relationships with the medical profession with implications for their understandings of their autonomy from and dependence on medical expertise and intervention. In this section I will highlight my participants' accounts of their relationships with midwives, GPs, social services, antenatal education classes and informal sources of support in the context of preparations for the birth and motherhood. In the process I will highlight how my participants' experiences of being in/visible relates to normative ideas about their capacity to give birth and care for their children as a disabled parent and linked to this evidence of a relative neglect of their core needs.

#### ***Medical support***

Preparations for childbirth, threw up issues of equal and fair treatment in a policy context of 'choice' around the type of birth, the promotion of 'normal birth' (without medical intervention) and location (Hadfield and Thomson, 2009). For some of my participants knowing that they would be treated (in Magda's words) 'as normal' in relation to birth was pleasing and understood as right and fair. While there is an element of trepidation in Magda's account surrounding the possibility of normal childbirth without intervention, she described a shared anticipatory experience with the other women in her NCT class and in online forums. This anticipation centres on her sense of anxiety about embodied independence and physical competence:

'It is not a case of someone making the choice for you...but on the other hand some of the things they (antenatal class) come out with makes you more frightened.....I came out and thought God what have I done?! (laughs, interviewer laughs) ...a lot of us would rather go in with an ignorance of what to expect...I thought I was the only one but everyone else agreed.'

In Amanda's case, while she was scheduled for an elective caesarean section, she appeared to reassure herself that many (able-bodied) 'short' women do the same due to small pelvises. Amanda felt so prepared and reassured by this knowledge that she decided not to attend antenatal classes as she felt they were designed to teach about natural birth;

'Amanda: I am scheduled to go in on the (date of surgery) so hopefully I will last that long I just don't know.'

Interviewer: And was that a c section?

Amanda: Yeah.

Interviewer: Was that your decision?

Amanda: No it was just one that was made, just purely because my pelvis, I know with a lot of women especially if they are quite small and slight, it goes with their pelvis and shoe size that is how they worked it out. And they said to me because you are short and chances are you are unless you have a really tiny baby you are going to have that so they kind of prepared me for that really.... .... I thought what is the point of going to the antenatal classes, I mean you can go it is very interesting but some of them I didn't find were what I needed to know.... yeah. I mean I know about ten people who have had children and I would say at least four or five of them have had caesareans. So there are a lot of



things, or maybe I shouldn't say this but there are a lot of things that you don't pay attention to.'

In some cases the option of extra support and their own knowledge and experience of the body and medical intervention appeared to make them feel more prepared and privileged. Amy was particularly reassured by her midwife that the hospital team would make provisions for her as a deaf woman and she was waiting for a tour of the hospital to be booked so she could meet the team. Drawing on her professional knowledge as a physiotherapist she described sitting back in antenatal classes:

'I felt like a bit of a geek because I knew all the answers ... .. I realised that actually I do know a bit more than them ... I have medical knowledge so that helps.'

In Magda's case, knowing the duty manager at the hospital meant that she was able to secure a private room in the hospital meaning that her partner could stay with her at night.

When I first got in touch with Kirsty, she was angry about her negotiations with her midwife about the possibility of a home birth. Kirsty and her partner had decided on a home birth so they would be able to stay together throughout and because Kirsty 'can't abide hospitals'. The couple had bought massage oils for her husband to apply during the birth and they planned to store medication in the fridge. Kirsty's midwife team, however, had argued for the need for shared care with an obstetrician which would mean that she would have to give birth in hospital. Kirsty struggled to make sense of the conflict with her midwife explaining:

'They immediately looked at my notes and put me down for shared care with the obstetrician ..which is a bit... it is kind of a bit ... I think to a certain extent it is

my leg that is the problem and not my head and not my problem, you know it is just literally one portion of my leg it is not anything else and I can't see how that means I should have shared care.'

Rather than focus on the physical elements of birth and the possibility of associated pain interacting with her condition, Kirsty appears to imply that shared care demonstrates her inability as a disabled person to cope with the mental challenges of natural birth. This belief is confirmed by her consultant's confirmation that her condition will not interact with her experience of birth:

'I wondered if I could have a contraction in my leg. But it is just sensory it is nothing else. (laughs) But I had to ask the question.... I wouldn't want to do anything that put the baby at risk.'

Kirsty's process of making sense of 'disability' in relation to embodied autonomy echoes her earlier discussion of the way in which she makes sense of 'disability' as something she can overcome physically as opposed to a restriction she must accept. In addition, her emphasis on mental capacity seemingly repeats the discrimination she faced in encounters with others when she first became disabled related to a diminished IQ and associated infantilisation.

### **Social support**

When it came to imagining the future, however, it became clear that being treated 'as normal' could result in neglect and invisibility. Most of my participants admitted to feeling anxious about physically caring for their baby in relation to their impairment:

'Social services have been a nightmare.. It has caused me so much stress ...worrying about how I am going to cope.' (Amanda)

‘I was just in tears ...I went into panic mode ... I didn’t want the support from the social welfare but where is the support....’ (Magda)

For Amanda and Lizzie support from social services became paramount. In Lizzie’s case becoming homeless in late pregnancy meant having to negotiate with the support of social services in order to access benefits and housing. Living in a top floor council flat Amanda was anxious about getting out and about while pregnant and negotiating the steps while carrying her baby. For Amanda a request for access to support was made without any fear of intervention. Despite asserting her need for support in the form of personal assistance she found the system difficult to negotiate. In contrary to the negative experiences and fears expressed by other disabled mother’s (surveillance would result in their children been taken from them) on the disabled parenting forums Amanda explained:

‘They all talk about people thinking you can’t cope, but actually I think you have to fight for anyone to really acknowledge that you have problems.’

Magda and Cathy did, however, talk about their fears of being under surveillance by professionals and services. While Magda appeared happy to depict her GP in a paternalistic caring role, she claimed she felt unable to confide in him about her fears of not coping with the physical demands of caring for her baby in case he got ‘the welfare involved’. Similarly, negative media representation of health professionals made her wary. This fear was compounded by her midwife’s refusal to explore with Magda the possibility of bottle-feeding despite Magda’s fears that she will be unable to physically manoeuvre her baby to breastfeed. Magda explained:

‘Okay I don’t see myself as disabled but other people do so how much are they going to see and then say oh well she is not coping very well. She is holding the baby wrong.’

Magda appeared to contradict herself by recognising her physical limitations and need for support but arguing that she does not see herself as 'disabled.' While Magda arranged a visit with an (independent) specialist centre that focused on occupational therapy ('I had to carry a dolly round in a sling') she appeared to find solace in both attending local groups and observing how women lift their babies. Mothering forums also appeared to provide a space free from surveillance where other women would joke about their reluctance to hold other people's babies on account of avoiding the risk of being covered in baby vomit, enabling Magda to normalise her feelings.

For Magda disability brings with it the danger of misrecognition as a deviant or incompetent in motherhood by professionals. Similarly, Cathy anticipating a meeting with her health visitor explained she felt 'concerned' about her attitude towards her capacity to 'cope' as a disabled parent. Her determination in the pursuit of embodied autonomy apparent in this extract appears to be threatened by the unknown challenges of mothering in the context of increased visibility with health and social care professionals.

'I've always had an attitude that I can do anything if I want to, you know, and there are ways round 99.9% of things, if you put your mind to it...when I was younger, you know, phew I'm trying to think of things I haven't conquered and there's not very many. .. people have asked me how I am going to bath the baby... I'm sure there's a knack, (laughs) ..... But I AM a little bit concerned about health visitors and midwives thinking, you can't possibly cope... .. but I have my husband I mean everybody needs help, nobody can do anything on their own can they? You know, very difficult to do it all on your own.'

Cathy described a conversation with her husband in which he had asked Cathy to:

‘Stay calm and be sensible... you can’t afford to get shirty... .. I don’t think I will (laughs)... .. I think it’s probably in my best interests not to be.’

Her husband draws attention to this negotiation with services as a particular moment in all of my participants’ biographies when much is at stake in relation to their own children. While Amanda and Lizzie see this as a moment in which they must assert their right to services, for Magda, Kirsty and Cathy the recognition (or not) of their physical limitations is balanced with the desire for privacy and fear of surveillance and intervention. Most of my participants appeared to use various disabled parenting forums and more mainstream sites on the internet for support and advice on the relationship with social services, the medical profession and for advice on equipment. Amanda explains that these forums are essential for getting advice from other disabled parents as otherwise they remain relatively invisible:

‘I think the reason I don’t know that many disabled parents is that they are just told to get on with it. That’s the thing so you don’t have this network of parents that are in the same position. I can go on the internet and say I need help on how to carry my baby can anyone give me any advice on equipment and people share ideas.’

My participants and their partners prepared for their baby by testing and purchasing equipment and researching online. This activity mirrors that of other (able-bodied mothers) and can be put in the context of the common culture of motherhood and distinctive practices through consumption (Thomson *et al*, 2011). In contrast to these cultural practices, however, the purchasing of equipment for these participants focused on practical needs and ways of trying to maximise embodied independence. This was particularly the case for Cathy, Magda, Kirsty and Lizzie who were concerned with restrictions and possible challenges caused by their physical impairment/condition.

Typically my participants purchased two sets of furniture, a Moses basket for downstairs and a cot for upstairs to save having to move upstairs during the day without support.

For Magda, Cathy and Kirsty, the support provided by their husbands was cited as a defence against the need for professional support or intervention. Despite this, my participants' accounts revealed that this support was not enough. In her case for personal assistant support Amanda argued:

'What they tend to do is say you have got a partner. But well he is at work all day what is he supposed to do - give up his job? And you are actually entitled to have help if your partner is at work.'

Not all of the participants in my study, however, had a partner as a source of support. Indeed, in Lizzie's case she voiced the possibility that her ex-partner may use her disability against her to gain custody of her daughter. Lizzie's account of pregnancy appears to highlight a turning point in her life in which declining social mobility has resulted in total isolation. Describing herself as a 'nomad' when faced with negotiating a home for herself and her daughter with local housing associations Lizzie explains.

'But you know when you are very determined there are ways and means of coping with these things.'

## **Endings**

Ending and leaving my interviews with my participants brought with it a range of complex emotions. In most cases, my field notes revealed a sense of absolute exhaustion after listening to their accounts as evidence of the intensity of the encounter. As I waited for the taxi to take me to the station after my first interview with Cathy, I couldn't bear to wait inside the flat, which I later described as suddenly feeling

‘suffocating, dark and oppressive’. Magda left me wondering if I had revealed too much and whether the familiarity and warmth of the interview encounter meant I had let my guard down professionally.

‘Feeling that professional boundaries have been blurred ... ..I think how much trust she has in strangers met via the internet ... .. Have I revealed too much? ... .. Perhaps I had to be a potential mother for the account to be told?’

As the interview with Amanda reached her 50-minute limit, she started to fumble for her phone insisting that she would call her husband and cancel her lunch. I wrote afterwards of my feelings of being ‘tested’ over how important her account was to me and ‘pushed and pulled emotionally’. Rather than let her cancel lunch, I insisted that we stuck to the original plan. I explained my rationale for this in my field notes as respecting her boundaries, however, it is also clear that I had the need to set my own boundaries: ‘after the interview I forgot about Amanda immediately and struggled to find the time to write up my field notes.’

Both Lizzie and Kirsty provoked feelings of ‘guilt’ as I left. Kirsty’s husband asked me if all my interviews were so short. Leaving Lizzie was even harder as I described stalling for time in the bathroom and wondering if I should put her in touch with friends in the area. I noted that she ‘practically had to push me out of the door.’

It is possible that some of the emotions I described upon leaving my participants could have mirrored my participants’ own emotions. It is imaginable that if I found listening to my participants’ stories exhausting emotionally that they were also emotionally exhausting to tell, particularly when combined with the emotional state of late pregnancy. Descriptions of my feelings of being confined in my interview with Cathy, of revealing too much in my encounter with Magda and the conflicting and challenging

feelings at the end of my interview with Amanda all appear to reflect elements of their respective accounts of autonomy, interdependent relationships and seeking support and assistance. My descriptions appear to capture some of the sense of helplessness, frustration and vulnerability that are imaginable but not explicitly voiced within their accounts.

My difficulty in leaving my participants or in engaging with their accounts on the other hand could be said to reflect my own fears related to the fragility and temporality of able-bodiedness. Further, it hints at the realisation of the part I have played in side-lining disability as something that happens to others, not my responsibility. It was only in my interview with Amy that I described feeling comfortable leaving. I wrote about Amy's sense of 'peace' through her religion and my own sense of pleasure at her neatly worked out account about her identity shifts from being deaf to becoming a Christian. Coupled with this I wrote of my pleasure and sense of achievement in conducting a free association interview with a deaf woman through lip-reading. This suggests that there is an element of the neatly worked-out, determined accounts that is easy to hear and that the intense emotionality of the interview encounter reveals the fragility of these accounts in relation to the anticipation of the future embodied life-course and relational challenges. The intersection of difference and commonality that forms the emotional context of the interviews appeared to implicate me through the process of hearing my participants accounts evidenced through my articulation of guilt, responsibility and desire (for motherhood).

## **Conclusion**

In this chapter, I have presented a series of journeys into disabled motherhood. I have also begun to illustrate the way in which difference created a troubling emotional dynamic in the interviews, signalling the start of a parallel journey over the course of



the research of emotional sense making. Bodies (including my own) become part of the conversation about difference, even when they are not explicitly accounted for (in language). The interview dynamic reveals key questions related to the significance of embodied difference. Am I disabled? Or am I like you? What does disability actually mean?

By drawing together all six cases I have highlighted cross-cutting themes or key moments within my participants' accounts in relation to ongoing 'body projects' related to the pursuit of autonomy where the embodied, emotional and social experience are tightly knitted (Shilling, 1993; Featherstone, 1991). 'Determination' is a key thread which apparently links together all of my participants' accounts of the experience of (embodied, social and sexual) autonomy. My participants appear to negotiate the possibilities for living a 'normal' and successful life, equal to that of their able-bodied peers. Central to this process, mirroring the experiences of other able-bodied women is their reflections on possibilities for choice and the synchronisation of education and career with motherhood in their biographies (Thomson *et al*, 2011). In this context, my participants' reveal key challenges over time related to their eligibility for motherhood and their similarity with or difference from others.

In conception and pregnancy and planning for birth my participants appeared to be generating new 'body projects' where they are faced with what they can manage independently with the help of research and expert knowledge (ovulation, pain relief to enable exercise, surrogacy, planning a natural birth, planning a birth in private space, planning deaf aware support in birth, sourcing baby equipment) and what requires a forms of inter-dependency or assistance from others (doctors, surgeons, surrogates, partners and support networks). Linked to this is the balancing of embodied knowledge, fears and foresight with the authority of medical knowledge and intervention.

In the process of mapping these accounts of determination I have begun to document key challenges in the process of negotiating autonomy, interdependency and assistance. Central to this experience is the contradictory feelings of being both invisible and highly visible in their encounters with others, particularly health and social care professionals and institutions. It is this paradox that captures the wider picture of how disabled bodies stand in direct tension with concepts of agentic, autonomous, healthy and desirable reproduction in relation to fertility, birth and motherhood and the more recent display and celebration of the 'pregnant beautiful' body (Tyler, 2008). As my participants negotiate and try to make sense of these experiences and the significance of their embodied difference, difficult emotions are revealed. I have presented evidence generated from our interview encounters of intense emotions; confusion, pleasure, hope and fear.

In the next chapter, I move on to my second interview encounter and my participants' accounts of their experiences at the point when their babies were approximately four months old. I will show how my participants' hopes and fears for the future detailed in this first encounter involved significant foresight as to the embodied and social challenges of childbirth and looking after a young infant.

## **Chapter 5**

### **Early motherhood (0-5 months)**

In this chapter, I will present aspects of all six journeys so far, when the babies were approximately four to five months old. In doing so, I continue to outline the emotional dynamic that unfolds over our encounters. In this second interview, the babies were also present and I found myself positioned as a curious observer of my participants' physical and emotional caring activities. In contrast to the previous interview, however, I consider whether this curiosity appeared to generate troubling emotions within the interview dynamic and to what extent my position was invited by my participants.

I begin my presentation of my participants' accounts in Section 1 with their reflections on their recent past experiences of childbirth relating these experiences to the in/visibility of disabled motherhood with consequences for their 'body projects'. In Section 2 I consider their experience of the everyday caring activities such as breast or bottle-feeding, focusing on their accounts of feeding their babies as evidence of maternal competence. I return at this point to some of my observations within the interview, recorded in my field notes to illustrate the way in which my participants carried out these activities in practice. These observations will be put in context with my participants' accounts of their increased visibility in relation to health and social services.

Shock forms the central motif within this chapter linking my participant's embodied experience with an increasing awareness of the way in which disabled mothers are excluded from normative expectations of maternal bodies. I will draw out the way my participants negotiated these challenges in relation to their experience of autonomy and a related sense of exposure in public and private space. In section 3, using examples from the emotional dynamic in Magda's case study I will illustrate the way in which the

emotional experience of disabled motherhood effects can be hidden or made invisible in the context of observance or assumed surveillance. I have chosen Magda's case study for this chapter because, in contrast to my other interviews, the 'easy' dynamic of the interview disguised the extent of the challenges she encountered. The work of making her experience intelligible provides insight into the challenges all my participants faced. Finally, I will conclude the chapter by returning to the emotional dynamic that unfolds across the fieldwork as I ended my first interviews with all six participants. By reflecting on some of the feelings evoked as I left my participants I will prefigure some of the themes that will become apparent in the final data chapter.

### **Re-introducing the emotional dynamic**

Following my initial interviews, contact in many cases was maintained by email by my participants or their partners. For some of my participants (Magda, Amy, Amanda and Kirsty) I was included in a collective round robin e-mail with information on the weight and date of birth and the name of their sons (Harry, Jacob and Ewan) and daughter (Louise). Photos were also included of mother and baby, and in Magda's case her partner dressed in surgical gown and cap. Cathy and Lizzie sent personal e-mails to me directly with more detailed information on the birth and how they had settled into a routine after the birth with their daughters (Jasmine and Esme). Cathy included pictures of herself bottle-feeding Jasmine practising skin-to-skin contact after the (surrogate's) birth. My inclusion in these celebratory emails gave me a sense of pleasure and relief, that in a small way I was regarded as part of their journey.

Despite these positive feelings of inclusion in advance of our meetings, the encounters themselves were complicated. In most cases I reported in my field notes a sense of 'getting it wrong' and a sense of intruding. Many of my participants appeared tired and interview accounts were stilted in stark comparison to the energy and zeal of their

pregnant selves. Of course, the babies were also present in this interview offering a distraction for my participants for whom my questions were no longer their main focus. The presence of the babies also raised challenging feelings for me as I observed different ways of physically caring for babies than I had become used to. My experience of feeling an 'outsider' can be made sense of in relation to the increased level of visibility of my participants' bodies in both public and private space during this period, for example through their interactions and encounters with health professionals and through mother-and-baby group settings.

My interview encounter with Magda, however, felt notably different. I described myself feeling 'drawn in', by a strong sense of identification (class and gendered). When she picked me up from the station some distance from her home in the summer 2007, I was struck by her energetic conversation as she told me in great detail about the birth of her son Harry, who sat occasionally sleeping in his baby carrier on the back seat. I found Magda's interest in my own life difficult. Despite anticipating this and deciding in advance that I wished to maintain my own privacy about emergent signs of fertility problems, by the time we had reached Magda's house she had given me advice about the use of herbal remedies to assist fertility and ovulation strips. During the interview I found myself caught up with desire to interact with Harry. This desire was encouraged by Magda, who insisted that I carry him out to the car after the interview as 'good practice'. I wrote in my field notes of my feelings of anxiety and desire in relation to my own infertility and motherhood leading to subsequent feelings of exposure.

## Section 1: Reflections on the past

In Chapter 4, I argued that many of my participants' expectant accounts highlighted the importance of being 'treated like normal' and that some anticipated the possibility of a 'normal birth'. I suggested that these birth plans confirmed their capacity for embodied autonomy and connected them to the 'normal' fears and experiences of their able-bodied peers. Yet some of my participants also worried whether their plans for a 'normal birth' would result in a neglect of their need for extra support.

In this section I focus on my participants' reflections on their recent experiences of childbirth, outlining the significance of childbirth as a key embodied moment in their life-course. I will present the accounts of Amanda, Kirsty and Magda highlighting how childbirth can be a disruption or confirmation of preconceived ideas about their capacity for autonomy and the desirability of their reproductive bodies. I will present the apparent emotional impact of this disruption and the means by which they made their experiences intelligible. I will then return to the issue of in/visibility in the context of recognising disabled women's needs in childbirth. Through Amy's account I will relate encounters with medical structures in relation to need and neglect and present her means of making this experience liveable.

The context of stretched resources within British hospitals at this historical moment is common to all women giving birth in the NHS context (Thomson *et al*, 2011).

Similarly, despite the maternity agenda for 'choice and capacity for a normal birth' at the time my participants' planned and gave birth, the common experience of first-time mothers reflects that of medicalisation (Hadfield and Thomson, 2009). What is pertinent here, however, is the way in which my participants make sense of their experience of 'shock' and relative neglect in relation to their status as disabled mothers.

So urgent was Magda and Amanda's desire to share the account of birth that it was told (by telephone or on the journey to the house for interview) before the interview had even begun. For Amy it was the only condensed account that was told before Jacob woke and the interview became dominated by continuous disruptions of difficulty breastfeeding, colic and restlessness. Yet there was no question that the story of birth could be avoided, however difficult. In my field notes, I noted how the 'disappointment of the birth hung in the atmosphere' of my interview with Kirsty. Both Amanda and Amy were still suffering from the physical effects of the caesarean section.

Amanda's 'angry' and 'confused' account about her status as a disabled (or 'short') person and her difference from other mothers appeared to reach a crescendo in relation to birth. Amanda described her attitude in pregnancy as 'idealistic...I had no idea' and her experience came as 'a bit of a shock'. The 'shock' for Amanda occurred when she began to relax about her own embodied fears related to not being able to carry the child to term. Amanda explained how she felt reassured by the finality of the surgery date and advice from friends and family that the baby would not come early. On the advice of her partner and friends she took a mini break with her partner and was initially 'pleased' that she felt physically well and less vulnerable than she had for a while. During this break, however, she began to experience debilitating Braxton Hicks contractions, resulting in a trip to hospital and an early caesarean section. Her birth account that followed highlighted a sense of confusion and powerlessness;

They had a bit of a discussion about what they were going to do. ....they took me in and did it at a quarter to eight in the morning so it was all a bit of a shock ... I came round and they handed him to my partner who was in the next room...I came round they gave him to me but obviously I was quite out.

(laugh)... I could hear a baby crying ... I was like, why is that baby crying.

Because I think you are so out of it you don't realise where you are (laughs).

Amanda's repeated description of the 'shock' of birth continued in her account of returning home three days later and being physically unable to care for him without support;

It was just such a horrendous time I don't mind admitting it. I was in a lot of pain and you can't move (.) felt absolutely dreadful... .. he had colic as well so he wasn't sleeping at all ... .. yeah it was just the shock of it all. (laugh) ... .. I had sort of baby blues. (.) He was crying so much it was kind of the shock of it thinking oh my god ... .. it was a huge shock, there is no doubt about that, I think because it wasn't the easiest of births it just sort of adds to the....'

For Amanda the real 'shock' of birth related to her sense of responsibility for her son - 'You just want to be a good mother, to be responsible' - and whether she had jeopardised her capacity to carry her son to term.

For Kirsty it was the debilitating pain in her leg once the contractions began that made the home birth she had finally negotiated with her midwife, impossible. Because she was unable to stand upright, Kirsty's midwife convinced her that it was not safe for her to birth at home. Kirsty was moved to hospital where she was administered with an epidural and gave birth without the need for surgery. Unable to have the private experience they had envisaged, Kirsty's account detailed the disappointment and horror of her birth through her partner's eyes:

'He just couldn't get in round to me to do the massage, there were too many people around, there was a lot of blood ... ..he said the last five minutes



were the scariest of his life. They were threatening me with as caesarean section if I didn't push harder. I did not want a caesarean... .. the whole thing wasn't what I was expecting.'

Contrary to Kirsty's expectation it was her midwife who appeared to enable Kirsty a sense of control within the birthing process:

'She was good; I take my hat off to her... She said do you agree you need to go to hospital? She made me feel like it was my choice'.

Kirsty connected the experience of loss associated with birth with her consistent account of self articulated in our first interview:

'It was just another thing my leg took away from me..... If I had been told there was even a chance of this happening there would have been a proviso in my thought process... my biggest thing, disappointment was the fact that I couldn't do it on my own and I felt a bit like I was set up to fail.'

The division of the leg from the rest of body and mind is characteristic of Kirsty's condition but it also does the important work of confirming her inability to birth without medical intervention.

'It wasn't my ability to cope with the pain in my tummy that was the problem it was my ability to cope with pain in my leg that was the issue.'

Kirsty's distinction between her 'ability to cope' with the two different sites of pain speaks back to the connection made in her first interview of the incapacity for a normal or 'natural birth' with the prejudicial idea that as a disabled mother she is mentally incapable (mind over matter). The disappointment of a medicalised birth was closely linked to her sense of giving the best for her child, 'I just wanted to avoid drugs in her (daughter's) system'. In this sense the division of her impairment from her experience

of mothering is paramount. The disconnection that Kirsty experienced in relation to her leg appeared to provide a way of making sense of and negotiating the experience birth in her account, enabling her to maintain a semblance of autonomy in the face of medical intervention.

Magda's account of childbirth, however, took quite a different turn. Magda appeared to protect herself from any perceived disappointment of a caesarean section, by repeatedly asserting that her body would fail to give birth naturally. The pursuit of a normal birth was recalled as a comical farce or game in which all the medical players move around her assessing the capacity for birth without intervention and finally deciding what Magda knew all along that she would need surgery:

'I kept on saying but my hips are wonky it is going to be a caesarean and they kept on saying no no no we will let you go through it naturally... .. I felt ready to burst and said look I want to go down now, I am fed up, it is every three minutes, so they took me down... .. I said get the epidural in now because of my wonky spine it is going to take a while ... .. when they took the needle out it was bent... .. I was on laughing gas and I just kept saying, give me the mask, give me the mask, and they kept saying, do you really need the mask? (laugh). And I thought, no but this is just so wonderful. (laughs, interviewer laughs) They took the mask off me. But then his heart rate dropped but I was so drugged up I wasn't too bothered, I mean there was panic inside but I wasn't too bothered I thought, they know what they are doing. Then this lady came, a specialist and she said, I will have a look and she said you can't give birth naturally, your hips are too wonky, we will have to discuss options. I said, what a caesarean, she said yeeesss, I said do it. Do it now. I mean there wasn't any discussion because I had said all along. (laugh)'

Magda appeared to enjoy the telling and listening of this birth story, emphasising her own agency and control over the process. Rather than normalise or deny the possibility of medical intervention, Magda appeared to embrace her need for support as a disabled woman in much the same way that she embraced the support and expertise of her GP.

Listening to the birth stories of Kirsty and Magda I was struck by the sense of foresight that they had revealed in the previous interview in relation to their embodied limitations in birth. Amanda's fears of her son growing too big for her to carry to term, Kirsty's seemingly irrational misgivings that she may feel contractions in her leg and Magda's doubts about her capacity to give birth without medical intervention were all realised. My own sense of 'shock' and dismay during these interviews related to a sense of injustice that their misgivings had been dismissed or placed aside, in favour of reassurance of equal treatment with able-bodied women and the normalcy of their birth plans. The extent to which my participants allowed themselves to imagine a 'normal' birth or in Amanda's case the idea that her experience of surgery would be like that of other 'short women' appeared to have significant emotional consequences.

The experiences recounted by the other participants in the study expressed a concern with making their particular needs visible and the accusation that their needs were neglected. Amy had already laid significant groundwork to prepare for her birth in relation to deaf aware practices and provisions. She drew on her expert knowledge and familiarity with the hospital setting as a means of asserting her needs with hospital staff and her preparations for planning her birth. In this second interview she explained that she had kept an open mind about the possibilities for a caesarean section because she has a curvature of the spine.

Despite her foresight and preparations for birth, Amy's needs as a deaf mother with a curvature of the spine were not addressed by the hospital staff. Amy gave her account of

birth in a methodical and factual way, punctuated by the instances of medical intervention (although this style of account also mirrors her communication style as slow and considered). Her birth was long and difficult. She explained that she had rejected pethadine because the gas and air made her so confused and unable to understand the sounds around her. She feared that once given pethadine she would be powerless to control its effects. Delays and staff shortages meant she was not given the epidural she requested. After labouring for 12 hours Amy became tired and unable to focus on what she needed to do because her midwife repeatedly covered her mouth while giving instructions:

‘It wasn’t the pain that was the worse bit or not knowing what was going on, it was the communication.’

Eventually following this breakdown in communication Amy was given an emergency caesarean section. She described her interaction with the obstetrician and anaesthetist as the first time her deafness was taken into consideration in relation to communication.

Following the delivery, her midwife told her:

‘I could have done more to prevent it, which is not what you want to hear from a midwife.’

After the birth Amy spent a night on the hospital ward. Despite her efforts to prepare the hospital for her needs as a deaf mother, no specialist support had been put in place to assist Amy in responding to her baby’s cries at night. On the first night her baby was taken from her to the nurses’ station and brought back when he cried: ‘which wasn’t really an option that I wanted to pursue but there was no other option.’ On the second night the nurses were unable to have Jacob in their unit so he was placed by Amy’s bed and the other women in her bay had to press the buzzer every time he cried ‘and it was a lot that night’.

Like Kirsty, Amy told her birth account from the eyes of her husband enabling her to assert her own professional competence:

‘He was trying to facilitate the communication. But he ended up being very frustrated in some ways more frustrated than me. Because he was the one witnessing the whole thing, and he couldn’t do anything about it. At one point he really wanted to say I want a different midwife, but he didn’t feel that he could because he was worried about how I would be treated afterwards. Which is understandable... .. I have been in a situation where patients have asked for someone different or made it very clear that they didn’t like someone. It is quite easy for someone else to treat them.’

Following the birth Amy was able to make a formal complaint about the lack of preparation for her specialist needs and blamed the labour ward coordinator as opposed to the nursing staff.

Amy’s account demonstrates the way in which medical practice and stretched resources can have a detrimental impact on disabled women’s experiences of birth. While Amy’s account of preparing birth enabled her a space to combine her professional status and expertise in birth this status is diminished as she becomes subject to discrimination and professional ignorance. It is only following the event that she is able to draw again on her professional experience to highlight bad practice and make the story of birth more liveable.

Both the portrayal of surgical staff in Magda’s account and Kirsty’s recounting of her midwife’s support offer examples of good practice in relation to communication and the balancing of medical intervention with a sense of autonomy. It is possible, however, that some of the shock and disillusionment experienced by Amanda and Kirsty could have been avoided if there had been more preparation for the potential ways in which

their impairments could interact with the experience of birth and recovery, and attention paid to their need for privacy and support in a medicalised context. In all cases childbirth played a key part in challenging my participants' 'body projects' related to their pursuit of autonomy and the balancing of autonomy with assistance and interdependent relationships.

## **Section 2: Embodied challenges in the present**

In this section I will focus on my participants' reflections on the early embodied challenges of breast and bottle feeding, nappy changing, lifting and carrying their babies. I begin by presenting the shift in the emotional dynamic of the interview as my participants finished telling their birth accounts while also responding to their babies' demands within the interview space. I then go on to look specifically at my participants' accounts of breast and bottle-feeding and their interactions with health and social care professionals and institutions. Finally, I will move on to present my participants' accounts of the resources they drew on in the form of equipment, personal assistance, mother-and-baby groups, parenting education classes and disability and parenting websites. It is through my participants' accounts of these interactions with others and resources that I present the way in which my participants' embodied experiences intersect with cultural constructions of disabled bodies as existing outside normative expectations of mothering practices.

My participants' birth accounts were closely followed by descriptions of the physical challenges after birth of breastfeeding, nappy changing, lifting and carrying their babies. After the recounting of the birth both baby Ewan and Jacob woke from their naps. Amy had been watching the lights on her baby monitor throughout the interview to check for Jacob waking. Once he woke it became virtually impossible for her to continue at the same pace as her attempts to talk and lip-read were disrupted by Jacob's demands. This

left me in a difficult position, wondering whether the interview should be abandoned or continued on Amy's insistence.

In my interview with Magda, baby Harry remained on an activity mat on the floor for the duration of the birth account happily singing to himself and wriggling as Magda and I sat overlooking him on the sofa. When he cried to be fed Magda established herself in position with a curved feeding pillow and fed Harry with a pre-prepared formula bottle as she described the challenges of winding after a feed. In my notes I described this as an enjoyable and harmonious time.

During my interview with Kirsty she broke from our position on the floor where baby Louise had lay between us soothed by Kirsty's singing and the playing of musical toys, to feed her. Kirsty prepared herself for the feed by covering herself and her daughter's head in a feeding shawl as she described her negative feelings about breastfeeding in public. I subsequently wrote in my field notes of the way in which I experienced this covering of herself and her daughter as firmly establishing my position as an 'outsider' in such a private and intimate context.

Babies' nappies were also changed in front of me or taken off and changed in a private room as was the case with Kirsty who took her daughter to the dining room to change her on the table. I described in my field notes my wondering as she shouted through to me as to whether this was done for practical reasons (save bending her back to the floor) or an act to create a sense of privacy and distance from myself as an outsider. In my field notes made following my interview with Cathy I reflected on the way in which Cathy had leapt up to change her nappy on the floor only to discover it didn't need changing. I questioned whether Cathy felt conscious of my presence as an observer particularly in light of her descriptions of feeling watched and judged ('waiting for me to mess up') by health professionals.

In addition, I also described my own feeling of discomfort as I found it difficult to interact with baby Louise while Kirsty continued encouraging her to lie on her tummy on a Lamaze spinning ladybird activity toy (designed to encourage babies to spend time on their front in preparation for crawling). In response to Kirsty's statement that it does not take much to communicate with a baby 'just a smile even if you don't feel like it', my field notes describe my concern as to whether 'I was a good enough visitor.'

With the exception of Magda, my participants had not anticipated the physical and mental challenges of breastfeeding in their expectant accounts. Magda, Amy and Amanda all described relying heavily on their partners in the first few weeks following the birth to help them lift their babies and establish breastfeeding. While Amy and Amanda described a point of realising how fortunate they were to have their husbands at home through extended paternity leave and redundancy respectively, Magda described her acute fear in hospital in being unable to feed independently once she returned home:

'I just burst into tears because Neil had to help me each time attach Harry and I thought this is going to be pointless when he goes back to work.... this lovely midwife said oh what is wrong and I said look I don't want to breastfeed anymore. And she said oh we thought you did it was in your notes and I said I can't do it anymore. I was getting to the point where I was not so much rejecting him but every time he was passed I wasn't comfortable.... I am not the kind of person who is comfortable breastfeeding in front of people.'

Aspects of the babies' health such as colic, reflux and poor sleeping also increased the physical challenges of feeding. While Amy found she was able to establish breastfeeding and gradually develop more physical independence once she healed from



the surgery, both Amanda and Magda turned to bottle-feeding, linking this shift to the emotional toll of the physical challenges of breastfeeding.

‘For my own sanity more than anything’ (Amanda)

‘For the first bottle that wave of love that you are supposed to get just came over me because it wasn’t seen as a challenge anymore’. (Magda)

Bottle-feeding, however, posed its own challenges. In Amanda’s case, it was very difficult to feed baby Ewan because of his reflux and colic, causing her a lot of ‘stress’ as she feared he was not getting enough. As Cathy fed baby Jasmine in the interview she described the way in which in the first few weeks bottle-feeding was hard because Jasmine was so small she ‘slipped through’ and ‘flopped down’ from her arms. Winding created particular problems for Cathy, Amanda and Magda. Magda explained that she was unable to wind Harry herself and neither her health visitor, nor other mothers online (disabled parents website) were able to come up with a solution.

By the time of this second interview, Lizzie and Kirsty had both established breastfeeding. Both were explicit in their accounts about providing ‘the best’ for their daughters through breastfeeding at the expense of their own physical wellbeing. Both had suspended their pain relieving medication to avoid it being transferred to their daughters through their milk. Kirsty explained that she had food allergies as a result of drinking formula milk and wanted to avoid the same experience her daughter. In contrast to their birth accounts, breastfeeding marked a new relationship with their bodies which allowed for a sense of agency and determination. Both drew on ideals of self-sacrifice and pushing their bodies to physical limits to describe the way in which they had persevered with feeding.

‘(Breastfeeding) gives you stronger sense of purpose because she is more important than anything and you have got to keep on going you have got to keep ... a smile on your face. (Kirsty)

‘(Breastfeeding) is a bit like running a marathon ... it does mean that I am more exhausted though and unable to go out and do mummy things like go out in the park’. (Lizzie)

For both Kirsty and Lizzie the embodied benefits of breastfeeding (nutrition and bonding) appeared to outweigh the assumed social benefits of not being so physically exhausted while caring and playing with their daughters. Their accounts demonstrate the way in which breastfeeding symbolises a form of embodied agency, independence and competence. Kirsty’s capacity to breastfeed and her knowledge and research on the subject gave her a sense of authority over and above the attitudes of medical professionals and formal antenatal teaching.

‘I don’t do it how they taught me in the lessons. I did it our way, how it works for us and she is obviously not starving.... But the number of health professionals that are so shocked that I am feeding her....it is strange how people are so shocked..’

Kirsty’s emphasis on the ‘shock’ of health professional’s reactions to her breastfeeding suggests that her commitment and capacity to breastfeed was unusual in the context of the general demographic of new mothers. This was heightened by her version of self-sacrifice in which her daughter’s needs are put above her own need for pain relief. Her questioning of the shock of others, however, also appears to echo her accounts of the way in which disability is infantilised and related to low IQ. This became more apparent to me when Kirsty repeated an account of an encounter during this period with her GP in her final interview when baby Louise had developed a chest infection. ‘Sick of going

to the doctors and getting nothing' Kirsty had taken her mother-in-law as 'back up'. She described how her GP had expressed surprise when her mother-in-law explained that baby Louise had only had her 'mother's milk in her mouth'.

'And I kind of went, oh, yeah (shrugs) it is her favourite thing in the world and he said, oh are you still feeding her? It is like: Er Yeah?! (laughs) It is kind of a case of what is so strange about that.'

In her final interview Kirsty extended her account of this encounter to reflect on her GP's response:

'... whether it is because he saw the stick or my age or what... .... ∴ (my mother-in-law) kept on deferring the doctor to me but he just talked over my head.'

In this context, we can understand the determination to breastfeed as an expression of maternal competence that counters normative expectations of disabled mothering.

Breastfeeding is encouraged within the UK by midwives and antenatal education, including the National Childbirth Trust, for its nutritional, emotional (bonding) and benefits to the immune system (Dyson *et al*, 2006). In Magda's account in the previous chapter, I presented the way in which this promotion could be mismanaged and misinterpreted as a form of 'pressure'. While her community midwife 'refused' to discuss alternatives with her, Magda turned to her own mother (who bottle-fed) and the support of women on internet forums to confess and support alternative (deviant) types of mothering. Despite this support Magda's account revealed she had not challenged the advice of her midwife or the 'pushy' staff in the hospital and kept breastfeeding in her hospital notes, while also requesting a private room to manage her difficulties. In contrast to the portrayal of embodied agency enabled through support in the medicalised

context of birth, her post-birth account depicted her vulnerability and fear of being misrecognised. Told by the hospital staff that her community midwife would visit her at home, Magda explained:

‘I said. I can’t, I can’t do it and they said why and I said because I have chosen to breast feed him she will just go mad.... They told me that it is her job to offer alternatives and she is supposed to give support whatever choice is made... my health visitor was apologetic about her and said any problems we would have solved before Harry was born. ... if we have another baby I am going to ask can I go somewhere else, unless she is going to back off on that issue.’

Magda portrayed her community midwife as a persecutory figure and Magda becomes the whistle-blower on her unprofessionalism. With the support of hospital staff and her health visitor Magda was able to turn her fear and vulnerability into assertiveness and justice. She went on to fantasise about a role in which she would counter feelings of guilt and judgement by telling other women of her experience. In this sense Magda used her position of needing support as a disabled mother as one of authority in which she can speak back to other (dis/abled bodied) women who are struggling.

‘I went to one of those breastfeeding cafes....And I was like Heellloooo (laughs). ..... and I am there on the bottle (laughs). Hi everyone I am chilled out mother, I am happy you know I am not struggling... I really felt like going round to breastfeeding mothers or pregnant women (in the breastfeeding group) there are alternatives, you don’t have to feel guilty I have never felt guilty...Well I felt guilty because I was made to breastfeed but as soon as I bottle-fed I was fine I bonded with him.’

This extract illustrates some of the core themes for Magda, Kirsty, Amanda and Lizzie in relation to breastfeeding. Magda's guilt relates to the discursive construction of breastfeeding in maternity policy and midwife practice as providing the best for your child physically and emotionally (related to 'bonding'). In contrast to Lizzie and Kirsty's 'determined' accounts of breastfeeding, however, Magda's perceived lack of embodied competence is normalised in relation to the embodied 'struggles' that all women face. Magda's presence, bottle-feeding in the public space aimed at assisting breastfeeding women, however, puzzled me. I was reminded of her statement in her previous interview that she is 'not the kind of person who feels comfortable breastfeeding in public'. It is possible that the public space created specifically for women who are 'struggling' provided her with a level playing field in context with her own embodied difficulties. She was able to comfortably repeat the theme in her pregnancy account of her own 'normality'. Her experience also suggests that in certain environments the visibility of the disabled maternal body (as incompetent and deviant) is able to pass unnoticed.

Equipment bought in pregnancy such as drop-sided cots were found helpful; buggies, highchairs and even changing mats/stations (without harnesses), however, posed unforeseen challenges. My participants' environments also became significant. For Kirsty, Magda and Cathy, everyday tasks were made easier by working within a limited space on a low level (the floor). While Cathy lived in a small ground floor flat, Kirsty and Magda were both assisted by their husbands on a morning by helping them move the equipment and baby downstairs for the duration of the day. For Amanda and Lizzie, working within the limits of rented (housing association and private) flats posed physical challenges particularly in relation to getting out of the building with the baby and lifting their babies in and out of the bath unaided. For Lizzie as a single mother and

for Amanda whose husband was working during the day, access to formal support and assistance became paramount.

Despite such foresight they found in motherhood that they had not anticipated physical challenges or failings in relation to equipment. Environments and the wrong baby equipment all appeared to contribute to their sense of living outside cultural norms in relation to consumption and motherhood.

For example, Magda felt that the failure to obtain the right equipment served to mark out her physical limitations:

‘I ordered the highchair it looked great on the internet but when I got it home the tray didn’t come off, And I know it sounds silly but it really brings home that there is something different that I couldn’t do.’

Kirsty and Lizzie discovered despite considerable research that the buggy they had purchased that marked out their difference from other able-bodied women in public spaces. In her expectant interview Kirsty described the way in which she had carefully lifted her handbag in and out of the buggies and cots in Mothercare as a way of imagining how she would be able to move her daughter about. They had purchased a Quinny pushchair because it was ‘really reactive, you can deal with it with one hand’ enabling Kirsty to use her crutch with the other. In practice the pushchair proved too heavy for Kirsty to collapse. This was particularly difficult when she attended mother-and-baby groups in local church halls which required her to collapse it while holding her daughter. After attempting to collapse her buggy she also had to expose her impairment further as all the mothers were asked to remove their shoes before entering the hall. Kirsty described how the combination of not being able to collapse her buggy and her visible impairment made her stand out in a room of ‘cliquey mothers’:

‘I know several other people in there have got the same pushchair and I asked them and they said oh we find it easy. Well maybe I am doing something wrong. It may not just be because I have to do it because I have to do it with more weight just on one leg. ... .. I walked in and (one of the mothers watching her walk on the side of her foot while carrying the car seat) was like OWCH!’

Lizzie also did a lot of research on buggies, picking one on an internet auction site that she felt was strong enough to support her weight. After birth Lizzie moved into privately rented accommodation. While her flat was a much more comfortable environment than the hostel she lived in previously it did not have the benefits of the support network she had built with staff and the other residents. In an attempt to get herself and her daughter out of the small flat she had rented, Lizzie found an art class on the other side of the city. Despite utilising the Dial a Ride taxi service she found that many of the taxis were not adapted for disabled mothers as they did not contain baby car seats. As a result, Lizzie had to purchase a separate car-seat which she then ‘strapped to the pram with belts’. Lizzie recounted with humour the way in which this made her stand out in public:

‘But it looks terrible, you feel like the Beverley Hillbillies or something. This ram shackle buggy contraption with the car seat on... I certainly can't carry her in the car seat but yeah I'm having to lift her from the buggy in the car seat in to the car. Absolute nightmare and my back is very, very bad.’

Amanda and Lizzie discovered that their environments posed significant challenges to their everyday experiences of motherhood. Amanda was still on the housing association waiting list for a ground floor flat, ‘holding out’ for a flat with a garden. Lizzie’s one bedroom ground floor flat was narrow and cramped meaning that she had to give away her mobility scooter. The pavement in the street outside was also very uneven making

Lizzie unconfident about venturing outside with a baby sling. These environmental barriers served to reinforce their sense of invisibility in public space.

Both Lizzie and Amanda struggled with the social services about their eligibility for personal assistance and suitable housing. In Amanda's case this struggle was discussed in her expectant account as she foresaw having problems physically lifting and carrying her son, getting up and down the stairs and movement outside of the flat such as shopping. In pregnancy Amanda had enlisted the support of her MP to challenge social services. She found, however, that while they would give her six weeks of care assistance following the birth, as was their 'legal obligation' any long-term support was denied.

'The reason they wouldn't provide any support was because I had been independent before. And I thought being independent before, being independent on your own and being independent with a baby is a totally different thing.....  
...they couldn't provide the care worker I had to find someone myself. And I said well who is going to take a job for six weeks... it was just horrific you know.'

The support of her MP appeared to be a turning point for Amanda whose expectant account and account of birth both demonstrate an experience of feeling her particular needs are neglected through her positioning as like everyone else. In addition, her health visitor was also found to be supportive and attended the council meeting with Amanda about her access to assistance.

'At the end of the day it is in their interest to, for me to be kind of looked after but it was really nice of her, because it is just another person there really to back up what you say'.



Eventually the council offered Amanda 15 hours a week personal assistance and found her an agency to provide her with applicants. Amanda's PA's both help her carry Ewan, assist with shopping and 'look after' Ewan.

'I mean I was really chuffed, really, really chuffed but just really angry.'

Lizzie explained the challenge of having her support needs recognised whilst also be seen to be coping:

'I find myself in a curious dilemma with the various agencies though. You want to look like you will cope brilliantly with your baby, but you also want all the help that you can get.'

Lizzie explained her strategy with social work professionals as they visit her and Esme at home is to appear to 'look like you are coping'. This account echoes the interaction she described in her expectant account with the support worker who neglected to give her any support to fill in for disability living allowance on account of her middle-class education. Lizzie suggested the result of this performance had a significant effect on the way in which her social worker responded to her needs:

'By the end of it I knew more about her than she knew about me. I can tell you now that her baby was just over 4 lbs and that she was a single mum and the baby was premature and how hard she found it to manage and all the rest of it. I don't know if she knows anything much about me [laughing]. But a lot of negative stuff too ... .... she was going on about oh you don't want to send Esme to school around here. And you're better off moving elsewhere... .. almost like you're too middle class to be needing our services, go away and leave us alone.'

The juxtaposition of Amanda and Lizzie's accounts highlights their different approaches to embodied dependency and claiming support. Amanda appeared to combine her need for support with the responsibility and 'best interest' of social services for her child, without any sense that this marks her as deviant. This echoes her anger as a child at the relative neglect she experienced as a disabled foster child. By drawing attention to this intersection I could infer that Amanda's familiarity with the system enabled a space in which to assert the rights of her own child. Encounters with social services were relatively new for Lizzie, I would argue that her interactions with her social worker reflected her desire to be recognised as middle class. Her description of the way in which her social worker tries to find ways in which to identify with her situation, mirrors my own reactions to her middle-class status following our first interview. In both cases, however, they are involved in a struggle to make their needs visible.

For Amanda and Lizzie assessment by social services was a necessity, but for Cathy, Kristy, Amy and Magda's case interaction with professionals was largely limited to visits with community midwives and health visitors, common to first all first-time mothers. As a result, the balance between wanting to be seen as 'coping' and recognition of their need for support was more explicit. Cathy's determination to be perceived as coping alone mirrors her resistance to social service intervention as described in her expectant account. She described her interaction with her health visitor directly in relation to being assessed and judged for her capacity to carry out physical tasks:

'I do feel like she is watching my every move waiting for me to mess up.'

The sense of tension within these interactions is also articulated by Kristy.

‘It is easier to change her on the table... .... but then Louise weed all down me and she just looked at me, kind of (pulls face) and I was just laughing, she must, she must have seen it before....I have got my system, I mean Steve’s mum leaves me alone with it.. But then it is like (my health visitor) wants to open the doors for me ... .. I mean I don’t even know if she sees it as a problem, it just feels as if she sees it as a problem. ... .. Are you keeping an eye on me because you think I can’t cope, are you keeping an eye on me because you have seen something to concern you or, and I would ask her every time because it would be, it ended up I got quite paranoid about it. She said oh no, she is very fine she is very healthy. If that is the case and you are not doing anything to help then why do you keep coming ... .. I probably know more than other people... ..I find her really I think judgemental is probably the best word.’

For Cathy and Kirsty it appeared vital to demonstrate to their health visitors their capacity for embodied autonomy without assistance. In doing so they left their own ‘systems’ of coping, which they assumed to deviate from normative parenting practices, open to observation and what they assume to be surveillance. Increased visibility was associated with a sense of frustration and paranoia as the health visitors offer no advice or support.

At the point of this second interview web based disability support groups appeared to be less central in my participants accounts, perhaps linked to their preoccupation with every day caring tasks. As a result, there was less discussion of other disabled parents. Magda described the disabled parents website as ‘all very nice but not that helpful’ in terms of daily support and as Amanda explained: ‘It is everyday things you need help with now rather than just general information.’ The one exception was Lizzie who had continued to use her impairment specific website while finding it difficult to get out and

attend local groups. Whereas in pregnancy Lizzie described herself as a 'poor relation' as a single mother on the forums, she explained in this interview that that was less of the case, perhaps because she had discovered the single parents section of the website. In addition, while Cathy had stopped looking at disability forums she had found the surrogacy support forum useful for getting reassurance from other parents about her distant relationship with her surrogate.

Apart from Lizzie all of my participants had attended some form of mother-and-baby group. Lizzie explained that while she would like to attend such groups she found the idea 'impossible' as her days are consumed with everyday tasks and childcare. Attending the baby clinic to get Esme weighed offered Lizzie a glimpse of other women's experiences as she overheard them exclaiming they were unable to get out of their pyjamas until 2pm. She questioned whether they had a shared experience.

'But I don't know if this is harder for me, it probably is than normal single mummies I think probably have their problems as well. ...] ....maybe it's just ordinary, or maybe I've just got an excuse for it now.'

Despite this observation the baby clinic was still presented as space in which Lizzie was marked out as different by other women. She described a woman noticing her psoriasis on her arms in the clinic and moving to the other side of the room. Attending postnatal and community groups also served to mark out my participants as physically different as Kirsty described earlier in this chapter. Amanda related her experience of walking into the room to her late teenage experience of feeling different, taking strength as she described from the support of her friend.

'Oh god I hate it, I hate walking into places even now. Yeah it is dreadful sort of like linking arms! That is exactly what we said there is power in numbers.'

Cathy's attendance of baby massage classes in her local clinic was cut short when the teacher offered to teach her at home. This left Cathy feeling 'disappointed' and isolated from the group. She appeared unclear as to whether this move is a form of discrimination.

'And I honestly wouldn't have minded either way really but I said okay, you know? (laughs) I didn't really make an issue to be honest. I should of. I suppose I should of. I don't know.'

Feeling visible and self-conscious in local groups was a strong theme in these accounts. As Amanda explained at this early stage of motherhood there is more emphasis on mothers interacting with one another as the babies 'don't do anything'. Both Kirsty and Amanda articulated their difference from the other mothers in class terms. Kirsty described the mothers as local and knowing each other since school, whereas Amanda makes a distinction between herself and the more middle-class 'mumsy' mothers in her 'wealthy area' who have given up work for their children.

Returning to their theme of common experiences Magda and Amanda relate their discomfort within the groups to that of all women. Both appear to take strength in other friends they have made with babies who share similar experiences and Amanda goes as far as imagining myself in the future attending the groups: 'I don't know if you will find this'. Magda imagines that if her NCT friends attended the same group they would also be cliquey. In the smaller NCT group she found support without judgement:

'I just don't know how well I would have coped without all these friends. I think it would be quite lonely to be at home because I am not originally from round here.... .... I know I can say: 'look I am feeling a bit down do you want to come round ... I know that they are not judging me thinking oh you know she is not doing too well look at the way she picks him up. They care, not judge.'

In this sense as with birth and breastfeeding Magda consistently draws on the experience of other able-bodied women in her account to make her own struggles liveable.

In these accounts of increased visibility in shared space, I have shown the way in which my participants are negotiating their interactions with other mothers. Class and - as we shall see in the next chapter - ethnicity are interwoven in my participants' account of their experience of difference in these encounters reflecting women's experiences more generally of localised mother-and-baby groups (Byrne, 2006). My participants also appeared to make connections with other mothers along class lines as a way of normalising their experiences; Lizzie as a single mother who may also struggle to cope and Magda as an isolated middle-class mother who is able to spot signs of isolation and depression in others. Where my participants reported feelings of negative visibility in the case of Amanda and Kirsty, class differences are drawn on to mark other mothers out as different from themselves. In some cases this process also translated to the interview encounter as by drawing my own status as a young childless woman into her discussion Amanda was able to position herself as a wise advisor.

### **Section 3: 'Hiding' emotions and 'coming out'**

The emotional dynamic in my second interview with Magda built on the rapport we had created in our previous encounter when I felt alarmed about the way in which I readily revealed much more of myself to her. Even before the second interview had begun I found myself hinting at my own difficulty to conceive and receiving advice from Magda about options to maximise fertility.

'I wonder before this interview if I will end up telling Magda, as before I am aware that there is something about Magda that leaves me revealing more about

myself than I would ordinarily. Magda instantly asks me. I am cross with myself for telling her.'

In the same way in which Magda appeared to normalise her fears of her physical difficulties particularly birth, breastfeeding and 'coping' with other (able-bodied) women, my own fears of infertility constituted another shared experience with Magda. The knowledge of my desire and anxiety coupled with Magda's new status as a mother offered her a powerful position within the interview. This relates to Magda's depiction of herself as a potential advisor for women who were 'struggling' to breastfeed. Similarly, in her discussion of her NCT group friends, she positions herself as someone who is able to 'spot' friends who may not be coping and include one woman (with learning difficulties) who the rest of the group have rejected on account of her 'oddness.' These accounts within the interview appear to create a sense of Magda as assured and confident as I describe in my field notes:

'I was struck by how positive Magda's account is and the easy dynamic between her and Harry.'

This observation contrasts with my own fears of feeling exposed and vulnerable in the interview encounter with implications for my professional sensibility. It was only on reflection of my field notes coupled with my notes during transcription when I began to realise the way in which I had missed moments of tension. I describe in my transcription notes the 'slightly frenetic pace' of the interview dialogue. When I shared both my field notes and interview transcripts in group supervision my supervisors highlighted the way in which a focus on my own situation had led me to overlook the weight of her comment made at the very end of her interview:

'No matter how hard it gets I am having another.'

In her final interview Magda revealed to me that shortly after this second interview she had been diagnosed with postnatal depression. After the interview a chain of events occurred beginning with the breakdown of her specially adapted car that enabled her independence and an incident where she was told to collapse her buggy before entering the church hall where her mother-and-baby group was held:

‘That really upset, and I thought hang on, this isn't just upset because someone's sort of asked me not to do it. Normally I probably would have said no that's discrimination bla bla and I thought no its just other things. ... .. And I said (to health visitor) partly hadn't said anything, because I was worried about social services getting involved, and she (the health visitor) said we have no worries about the way you're bringing him up and coping. We don't get them involved (laughing). Because all the time I'd been hiding And I felt really annoyed then, because I thought well I would have seeked, sought help earlier but because of that fear you just think...’

Magda's revelation that she had been 'hiding' postnatal depression provoked a sense of my own shock and guilt (related to a sense of responsibility for noticing her emotional well being) as I articulated in my final set of field notes. Magda explained she had been 'careful' to give the right impression of coping to her health visitor and GP. Ironically repeating Magda's theme of a shared experience with other women, Magda found that most of her friends in her NCT group had also been diagnosed with postnatal depression.

‘And we all sit there and, but we'd all been hiding it. It was only when one of our friends suddenly just burst in to tears at another group and said how she was feeling about her son then we all sort of came out..’



Magda revealed, however, that 'coming out' (as postnatally depressed) was a complex process in which only a particular version of (Magda's) postnatal depression was given. She described how her health visitor took her through a questionnaire/check list to check for signs of postnatal depression which was repeated with her GP. Both reassure Magda that the way she was 'feeling inside' was not as a result of her 'feelings' (bonding) for her son.

'But the health visitor said I don't have any problems about how you feel about him it's how you're feeling. So she said there's no point in you going to the (postnatal depression support) group cos you're fine with him, so yeah. I'm just on some tablets (laugh). My GP said, "You know we thought that you may be (post-natally depressed) because of being disabled. And not just coping emotionally but coping with all the physical things, just build up and build up and build up so."

In a very similar way to Kirsty's strategy of dis-attaching her experience of impairment from her capacity to birth (and by association maternal competence), this division of difficulties caused by impairment from mothering (as emotional work) appears to reassure Magda. She is set apart from the other mothers in the postnatal depression support group who find problems 'bonding' with their child. The prescription of medication as opposed to counseling also appears to validate this distinction. While this assertion of her ability to bond with her son may set her experiences over and above that of her peers, Magda reveals the perceived danger of revealing too much:

Interviewer: Yeah and do you think that was different for you than it was for your friends in the NCT group?

Magda: Yeah because they're not disabled. I thought well you know, would it be on the record oh she's got postnatal depression and disabled. We'll get social

services in. But they said no we only get them in if obviously if he was covered in bruises every few minutes that weren't normal bruises or that he was starving.'

Therefore, for Magda, the danger of revealing too much was increased visibility in relation to social service observation, potentially compromising her role as a mother. Throughout Magda's account of motherhood she repeatedly insisted that she had bonded with her child, underlined by the medical diagnosis of postnatal depression, related to her physical limitations. Yet at her own admittance, overcoming the physical limitations of breastfeeding by using a bottle afforded her the experience of 'that first wave of love you are supposed to get.' Therefore, physical limitations were linked to her sense of emotional attachment to her son. The extent to which this can be fully revealed or acknowledged in interactions with professionals is questionable.

Following the last interview with Magda my field notes record a change in the emotional dynamic between us:

'We are able to talk more in this interview about how hard it has been and still is for Magda. Magda is now on medication although her mood still appeared to be relatively low. I also make a point of acknowledging that it has been hard for her and is hard for her now. This feels quite comfortable the whole interview feels like a calm acceptance, although there are some accounts/statement I find difficult to follow up.'

These notes reveal a greater sense of confidence in my own position as researcher. Despite this I recognise there are still some limitations and barriers to what can be said, suggesting that even in the calm space of the interview there are still potential risks for Magda. Conversely the risk for myself as the listener is that some things may be too

difficult to hear, particularly as I drew the final interview to a close, knowing that I would not meet with Magda again.

## Endings

Leaving my participants following these second interview encounters felt hard. My field notes (usually written on the journey home) revealed a struggle with difficult, 'depressed' and 'heavy' feelings. Following my interview with Cathy for example, I wrote of my fears for her in the future in relation to coping and my difficulty of where to place these fears in relation to my own desire to present a positive account of disabled motherhood. While I anticipated the legal surrogacy arrangement would go through smoothly I imagined it would cause her some stress. In other cases I found it difficult to engage with the experience of the encounter once I had left. For example after my interview with Amanda I delayed writing my field notes for weeks, choosing to read on the journey home rather than engage with my experience of her account and the encounter mirroring my emotions following our first interview.

The intersection of difference and commonality also played a significant part in the emotions produced upon leaving where I appear implicated feelings of denial (of our similarity), guilt and responsibility. Following my interview with Kirsty I felt that she tried to draw me into reflecting on my own emotions.

'In the car on the way to the station Kirsty begins to ask if listening to her account has made me think whether it could happen to me, before quickly changing the subject.'

I left her question hanging in the air and in my hastily written field notes denied any sense that I could imagine experiencing her situation. I wrote in my field notes following my interview with Lizzie:

'Feeling unsatisfied despite working my way through my questions' the sense that she is literally 'nudging me out of the door' mirroring our interaction in the previous interview.'

These feelings of what appear to be guilt were complicated by my feelings of rejection and intrusion into their private space, as I question my role and responsibility for my participants:

'I ask Lizzie if she has any reflections on the process of the interview and she says, well no I just hope you turn it into a book. And I blabber on about that being one aim but also journal articles and conference papers.'

This questioning of my professional role and responsibility for my participants also reflected the way in which my own feelings of invading their private space reflected their accounts of professional surveillance. Following my interview with Amy I found myself frustrated, my field notes consumed with the sense that I had failed as an interviewer to enable the production of a coherent interview account once Jacob entered the room. I questioned whether I had produced any useful data at all and if I should have abandoned the interview much earlier. One exception, as described earlier in this chapter was the easy dynamic and sense of enjoyment experienced in my interview with Magda.

## **Conclusion**

In this chapter I have presented my participants' journeys into disabled motherhood, and my own processes of engaging with difference. I have illustrated the emotional dynamic that arises from the experience of difference. I have shown the way in which my participants' bodies and the bodies of infants become part of the conversation about difference, even when they are not explicitly accounted for (in language)

By drawing together all six cases I have highlighted cross-cutting themes and key moments within my participants' accounts in relation to the disruption, confirmation and re-making of my participants' body projects. These projects relate to the pursuit of autonomy and the acceptance of interdependency and assistance. My participants' accounts reveal the changing meaning and significance of their difference from others and the implications for their sense of their eligibility for motherhood at this time. The theme of 'determination' that was so clear in our original encounters becomes muddled by embodied challenges and encounters with others. Determination has given way to 'shock' of childbirth and the embodied and emotional challenges involved in caring for a young infant resulting in a sense of vulnerability, fragility and confusion."

Despite the increasing awareness of the need for extra support, my participants' pursuit with the everyday activities involved in caring for their babies demonstrate their resourcefulness as they engineer new methods of 'coping' autonomously and with assistance. As I have documented the practices of breast and bottle-feeding appear to present my participants with new body projects linked to both embodied and maternal competence. Yet my participants' accounts also highlight constant reminders that their experience is on the periphery of normative cultural constructions of mothering. This is clearly evidenced in their experience of health and social care institutions, related expert knowledge and systems, public and private environments, baby equipment and interactions with professionals. All of which fail to fully address disabled mother's specific needs, rendering them either invisible or a presence subject to surveillance, prejudice or as simply standing out as visibly different from others.

My participants' accounts reveal considerable work to integrate these experiences of difference into their existing strategies of sense-making - drawing on their own professional expertise, knowledge and middle class status, separating impairment from

mothering and disability, and overwhelmingly; by drawing on the similar experience of other able-bodied mothers and women to make disabled motherhood liveable. What is striking, however, about the accounts gathered in this chapter is the fragility of my participants' attempts to make their experience intelligible in a period when their existing accounts of themselves (as determined) are disrupted by bodily change.

This fragility is evidenced in emotions, not only those articulated within my participants accounts, but those that sat with us in the interview and stayed with me once I had left. My participants and I appeared to be locked in a discursive space that made the revealing and observing of difficulties, emotional and embodied, difficult. The depression, guilt and fear I took away with me could well mirror what was unsayable within my participants' accounts. Moreover, the position of 'curious observer' becomes more uncomfortable when faced with the implications of our 'difference' both embodied and social, or to put it another way; the realisation of my privileged position as an able-bodied woman. My capacity to be held to account for the presentation of my participants' journeys without prejudice, and the questioning of my responsibility for my participants' wellbeing all served to magnify these emotions.

Returning to Magda's experience of depression, I have felt some trepidation about making a link between her experience of impairment and her capacity to 'bond' with her child. But I do so not to imply a direct correlation. Rather, Magda's example shows how the lack of appropriate support and the limited discursive space available for disabled women to present the challenges of mothering can compound the experience of new embodied challenges. Continuing the motif of in/visibility across the data set she demonstrates the part disabled mothers can play in making their experiences invisible. For Magda, the danger of revealing too much was increased visibility in relation to

social service observation and potentially compromising her role as a mother. These points will be discussed further in Chapter 7.

In the next chapter I will reveal how this analysis of the emotional dynamic within this second stage interview, demonstrates significant foresight as my participants reflect back with greater clarity on the embodied and social challenges of childbirth and of looking after a young infant.

## **Chapter 6**

### **One year after birth (12-18 months)**

In this chapter, I continue to map the series of journeys into disabled motherhood. I will present aspects of all six journeys so far, at the point at which the infants were aged between 12 to 18 months. In doing so, I continue to illustrate the changing emotional dynamic in our interactions. I start the chapter with a consideration of these processes, drawing out the way in which this interview encounter captured an easy dynamic as my participants reflected with hindsight on how far they had come. In this third interview, infants (now toddlers) were also present and I found myself engaged in lively interaction as I observed and recorded my participants' experiences. This dynamic contrasts with the more difficult feelings described in the previous two chapters; suggesting an element of resolution or acceptance.

The chapter will explore the themes arising from these third interviews at this particular biographical moment (12-18 months into motherhood). I begin my presentation of my participants' accounts in Section 1 with their reflections on the embodied challenges of the first year of motherhood, drawing out the experiences of their children's development and for some the parallel challenges of their own deteriorating health or impairment. In this context I present my participants' accounts of increased visibility in their interactions with health and social care professionals, family members, other parents and members of the public and/or a sense of invisibility or neglect. Speaking to their capacity for (autonomous) body projects, these accounts accentuate patterns of sense making in relation to their experience of disabled motherhood. The presentation of the specific and common experience with other mothers and disabled people within my participants' accounts offers a means of tracing patterns of acceptance and resolution.



In Section 2, I present the issue of increased visibility in public space in more depth. I will use examples from the emotional dynamic that unfolds with Lizzie over the three interviews to illustrate the way in which she played with the boundaries of visible and invisible difference, speaking to gendered ideals of the body beautiful. This performance was carried out in a particular geographical context, with race and class intersecting in ways that made her strategies for sense making seemingly precarious. Lizzie's concern with the gendered appearance of the disabled body was striking in relation to its relative absence in the other participants' accounts, suggesting she dared to challenge what is unspeakable.

In Section 3, I move on to present the parallel projects of my participants' children's physical and social development in relation to autonomous, healthy and attractive bodies. I will put forward their presentation of their child's increasing awareness of their mother's physical limitations, the contrasting of their children's development with these limitations and their parallel 'body projects' as they focused on teaching their children to be autonomous. These accounts reveal new and creative ways in which my participants made sense of their experiences of disabled motherhood, equalling or elevating their capacity to parent successfully with or above their able-bodied counterparts.

Finally, I conclude the chapter by returning to the ending of the interviews, summarising the emotional dynamic that has unfolded across the research encounters. I present the way in which my participants reflected on my interpretations and voiced their hopes for the impact of the study in the future.

### **Re-introducing the emotional dynamic**

The final interviews with my six participants were marked by a significant shift in the emotional dynamic. With hindsight I was able to see that my field notes revealed a more

coherent sense of my own emotions in relation to the previous encounters, particularly as I had begun the process of data analysis. Email and telephone exchanges to establish the final interview also suggested that my participants were reflecting back on our previous meetings and preparing what they wanted to share with me.

The descriptions I gave of my arrival to each interview within my field notes captured a positive sense of ease. I described the setting at Cathy's small flat as 'warm, lived in, relaxed, cluttered with brightly coloured toys' and Cathy herself as 'welcoming and enthusiastic'. Occurring after Jasmine's first birthday I described the interview as having a 'celebratory tone'. As we began to talk before the interview Cathy exclaimed: 'Turn the recorder on now!' laughing. At Magda's house I sensed relative 'calm' in contrast to what, in retrospect, I described as the 'manic frenzy' of the previous interview. We sat side by side on the sofa with Harry playing in front of us on the floor and occasionally joining us offering us toys to look at.

My appointment with Amy was timed to fit with Jacob's mid-morning nap.

Unfortunately, having walked instead of arriving by public transport from a nearby hotel, I arrived late having found myself lost in the new build estate in which she lived. After spending the first 15 minutes watching the monitor Amy brought Jacob downstairs. He then proceeded to embark on lively interaction with Amy and myself, lifting items from my handbag and bringing books for us to read. Prepared for the limitations this would bring to the interview method I found myself relaxing into a different form of communication in which, mainly through observation I was afforded a glimpse into Amy and Jacob's everyday life.

Arriving at Lizzie's, I recalled feeling 'more comfortable' than I had in the past, Lizzie as more 'relaxed and happy' and the domestic space as more 'organised and homely with hats and musical instruments displayed on the walls.' Also present at Lizzie's

interview was a cleaner who mopped under our feet as we talked and a social worker called her on the telephone half way through. I described the way:

‘Lizzie chats and jokes and uses pet names (on the phone) in a way that makes me initially think she is talking to an old friend’.

This led me to question in my field notes whether my feeling of comfort reflected a sense of feeling less responsible for Lizzie. Her daughter Esme played contentedly for the duration of the interview in her play pen in the corner of the room, breaking off when she appeared to realise she was the topic of conversation to laugh and smile with us. Despite this I record my own sense of discomfort of watching Esme fall asleep in a bundle on the floor, and a desire to lift and hold her echoing difficult feelings described following previous interviews with other participants.

In other encounters I found myself faced with emotions that had apparently been suppressed in previous interviews. For example I could not help but reflect on chance as a strange theme in our exchange when Kirsty became concerned about my own wellbeing travelling such a distance in bad weather on the interview date: Friday 13<sup>th</sup>. My sense of unease compelled me to broach Kirsty’s difficult question (posed in the previous interview) as to whether I could imagine myself in her situation. I realised that I had strong defensive feelings about the potential temporality of my own independence (as a young and healthy, childless woman). In retrospect I questioned whether these (hidden) negative feelings or fears had contributed to my sense of discomfort and of being an ‘outsider’ in our previous encounter. As I explored in my notes made at the point of transcription:

‘Rather than this being a one way process, my feelings of exclusion and discomfort could also have been related to my own efforts to distance myself from Kirsty’s experience.’

I was also confronted with the danger of over analysing my participants' emotions, potentially clouding my own capacity for empathy and understanding. It took me four months to track Amanda down via a disabled parents' website (from which she had originally responded to my request for participants). In a rushed phone conversation she mentioned 'a lot had happened'. Amanda called and rescheduled her interview three times due to illness making me wonder if this was a form of test for me about the value of her participation. In contrast to the strict timeframe set in previous interviews, however, Amanda explained she had no engagements and had timed the interview to coincide with Ewan's midday nap. I noted in my field notes a more relaxed and comfortable atmosphere between us. Amanda enquired about my own plans for the future including my feelings about having children in a way which did not feel intrusive. Having learnt of the illness that had developed since our last interview I questioned in my field notes whether I had read too much into what I understood as boundaries at this time. Perhaps my patience in constantly rearranging our interviews in relation to illness communicated acceptance, value and ironically a sense of understanding.

### **Section 1: Reflections on the past**

As we settled down to begin the interview it felt natural to comment on the obvious development of the children, whose lively presence in the interview was in play. This development provoked mixed emotions for my participants. Many expressed a sense of relief as they looked back at the physical challenges of birth and early motherhood. This was particularly the case for Magda whose diagnosis of postnatal depression was linked to her realisation of the emotional toll of her physical difficulties with little assistance. Reflecting back on the physical struggles of feeding and lifting and handling, Magda

explained the way in which Harry's development made things increasingly easier for her as he could 'toddle' to the car when he became too heavy to carry.

'Everyone always says ohhh you won't want him walking, it's a nightmare. But for me it's not its easier I look forward to it... he will be running next.'

For others, however, this increased mobility posed new physical challenges. Cathy reflected on the limitations she faced in lifting Jasmine which began when she started to roll off her changing mat:

'She is just off like a rocket. I am like, what am I going to do? It is a real panic.'

In the previous two chapters, I documented some of my participants' fear in relation to potential intervention by social services. In Cathy's case as Jasmine became increasingly active and wriggly at approximately five months old she dropped her in front of a team of health visitors and midwives at her local baby clinic. This incident lead to a visit from a social worker who was reported to be relatively unhelpful in coming up with a practical solution to Cathy's physical difficulties.

'I went to lift her and I dropped her. I just felt really upset and I started crying actually. Dreadful. Stupid thing to do really. But I did and they panicked... ...  
... She was fine. It was me ... .. But the reason I got upset was that nobody was actually helping me. I mean Ian was but he was at work.

... ..

They got a social worker involved ... .. I was a bit sort of oh god here we go you know. A bit, well to be honest I was really worried about that it really upset me... .. they said well what do you need, I don't know, there isn't anything, there really isn't anything, it's just a stage ... .. they were completely useless.'

Cathy went on to describe an encounter with her sister following a family bereavement in which her sister tried to give her advice about how to manage Jasmine's crying.

'Because it was not that long after the incident with the clinic I just got so angry. She was saying oh I would do this. ... .. I said look I was really quite pissed off with you yesterday to be honest, you actually made me feel quite inadequate. Undermining me as a mum ... .. it had nothing really to do with being disabled it just made me feel you know, but I guess I was feeling vulnerable after the previous incident ... .. I am just glad I am coping as well as I am.'

Cathy's account illustrates the intense emotions linked to her increased visibility as a mother and the fear that others would think she was not coping. While Cathy's worse fears were not realised there is still a sense that there was a limit to what could be made visible to others and relief that she had not lived up to perceived negative expectations. Cathy continued to use evidence of her physical capacity to cope without assistance as a strategy for making sense of her experience, rejecting any negative associations linked with disabled mothering. She had also continued to attend mother and toddler groups with her daughter and had begun to train as a helpline counsellor for the surrogacy organisation seeing it as her 'opportunity to give something back'. Yet it was her orientation towards attending a local disabled parent's support group that led me to note a significant shift away from her perspective in her first interview that she was not the 'type' of disabled person to 'join groups'.

'Yes I am going to go. I don't know what it will be like, if it will be any use. Because I don't actually know any disabled parents. Even though I know they are out there. I don't see myself in a big way as being disabled. You know sort of define myself like that. But obviously I am ... .. I guess I have become more bolshie about it... .. I don't think people expect disabled people to

have children really, they don't really you know. They don't expect us to do anything, let alone have kids. ... .. I don't make a big deal out of it. ... ..

I am quite independent. I don't like people interfering but it also annoys me when you ask people for help and there isn't any.

Cathy anticipation about attending the group reveals the way in which her experience in early motherhood has apparently strengthened a sense of common political experience with other disabled parents on the basis of a lack of support and resources.

At this interview, I also heard from Kirsty, Amanda and Lizzie about their unexpected deterioration in health. Kirsty's health began to deteriorate shortly after the second interview, her walking became worse meaning that she had to use a wheelchair and the pain and frustration reached what she described as 'crisis point.' At the same time her daughter Louise developed rapidly, crawling at six months and walking by seven and a half months. Although she had been a good sleeper at four months, Louise began to sleep badly and Kirsty's lack of sleep caused spasms in her leg. Kirsty also became pregnant with her second child and felt determined that Louise should be walking and talking by the birth to make things easier. Returning to the theme of neglect that reoccurred through each of her interviews, Kirsty described feelings of frustration and powerlessness as she and Steve travelled across the country to try and get support from the specialist centre but were left 'to get on with things' for six months. The couple had eventually turned to the extended family for support, staying with them while they moved to a bigger house with suitable adaptations for Kirsty's wheelchair.

'I was worried at first about them interfering but it is surprising how quickly you take it for granted. No they have been great.'

In this final interview account, Kirsty described a significant shift away from her perception that she was being 'judged' as a disabled mother who could not cope by her

health visitor. Reflecting on the invitation she was given by her health visitor to attend a Sure Start community group she argued that her inability to engage with her specific needs reduced her to a statistic, labelled along with other minority groups.

‘I’m not worried about her judging me anymore. I was worried that she’d kind of pay particular attention of the fact that I was disabled... ..it was more to do with the fact that statistically I ticked a nice box. The lady down the street she’s not from this country, she ticks a nice box. Originally, I was kind of a bit more sceptical and kind of thought it was because they thought I was rubbish ... .. I think at no point has she actually looked at my disability and how it impacts on me or Louise. ’

Kirsty’s new perspective on her relationship with her health visitor thus appeared to shift from preoccupation with embodied autonomy (proving she can do it) to an understanding that system of support available to her was discriminatory. Kirsty was thus able to merge her fears of prejudice as a disabled mother with her ongoing account of the neglect of her (impairment specific) support needs.

Kirsty’s acceptance of help from her in-laws when her health got too difficult related to the recognition of the ‘sacrifice’ she has made in becoming a mother:

‘My father-in-law said I gave up a year of my life quite happily to look after her, I invested a year. And I think, I see it as an investment... so they are quite happy to do their bit in return.’

While Kirsty was able to accept support from close family a phone call from social services enquiring as to whether her partner would like to attend a careers’ support group was met with disdain for failing to recognise the kind of (practical and medical) support they needed as a family. The subtext of this disdain was the idea that she was



been 'cared' for by her husband and that as a result it was him that needed emotional support. Returning to the negative encounters she experienced with other mothers in local community Kirsty explained that more of her friends had begun to have babies so she spent time with them as they shared the 'same headspace' and came from the same 'point in life'. Rejecting community and public health service support in this way Kirsty was able to continue the theme present across her three interview accounts of the couple as privately sufficient (with support from close family and friends); a form of autonomy with assistance that does not challenge her concept of herself as competent and respectable (as a married, educated, professional, middle-class woman).

Lizzie and Amanda on the other hand accepted support from social and health services as a necessity. This became even more pertinent with the onset of their worsening health. Lizzie reported that it had become increasingly difficult for her to physically care for Esme as she grew heavier as her arthritis had begun to worsen. Esme had become more active and energetic leading Lizzie to conclude that she needed to get out and take her to local toddler groups. Unfortunately, two weeks before the interview, she had become ill and bedridden due to the new medication she was taking, making it virtually impossible to care for Esme. Support, however, had been granted by the social services and she was visited by a personal assistant every morning ('so I am not as stiff'). She was given a further two hours a day once she became ill, giving her more energy to eventually travel to and attend the local toddler group. To access this support Lizzie had to navigate the system of applying for direct payments. In describing this process Lizzie crudely linked the reluctance of social services to offer support with their budget limitations, resulting in the degeneration of disabled people through basic care:

'They are just concerned with things like bottom wiping, you know if somebody is disabled they need their personal hygiene attending to...maybe they get their

meals from meals on wheels.. And that's where it begins and ends... that is the reality on a budget.. ... but the gap is just too great.'

Lizzie suggested that social services 'act as if disabled parents are a thing that had never happened before' linking this experience of neglect with surveillance, arguing that restrictions over direct payments (discouragement from the council) act as a way of 'policing' people. Echoing her experience in pregnancy she highlighted the complication of navigating both child and adult services.

Considering the dominance of Lizzie's middle class status in our previous encounters and interview accounts it is imaginable that this interpretation of her increased visibility and experience of neglect felt particularly difficult. Yet Lizzie attributed her recent success in establishing personal assistance to the fact that as an educated person she knows her own rights and is difficult to 'fob off.'

'This sounds a really pompous thing to say. I'm well educated and I can understand the stuff really quickly... I am not, maybe a typical client from that perspective. No no siree. I get treated very differently but I'm also much more difficult to fob off. [laughing] cos I know that I am not being treated right... ...  
... I've never really fitted well in to any particular box so.'

Lizzie appeared to have reached a sense of resolution in relation to her troubling position of not fitting into any particular 'box'. In contrast to her previous accounts in pregnancy and early motherhood of her class position working against her in terms of services meeting her needs, she appeared to have found a way of successfully marrying the two. Lizzie extended this success to her political participation, where she attended local council meetings about services for disabled parents and direct payments, continued participation on a disabled parents' website and volunteered as a local helpline representative for a disabled parent's charity. In doing so she appeared to find a

channel for the 'determination' that was present in her early accounts of becoming a disabled mother, through claiming her rights and that of other parents;

'I'm sort of determined to go and participate in those things no matter what.'

Ironically, success in being heard by social services also appeared to mark a turning point in her biographical account, where she was listened to and recognized as a disabled mother in need of support. In this interview Lizzie, (echoing earlier accounts) spoke of her family's failure to recognise her arthritis describing a time she stayed with relatives on a fold out bed and was mocked for being 'like princess and the pea' for complaining. She also recounted how after an elderly relative died the family failed to pass on the mobility scooter to Lizzie: 'That just shows my family's attitude to arthritis'.

Despite this apparent resolution, Lizzie described difficult feelings related to the perception of others that she was 'not coping' because of her inability to participate in groups. Increased visibility in public space appeared to threaten the careful process of sense making by which she had begun to make her position as a disabled mother liveable. She explained the attitudes of others made her feel 'angry' considering the amount of effort, organisation and commitment it took to get to the groups. The day before the interview the mother-and-baby group invited a lady to do nursery rhymes with the group with actions and dancing. Lizzie explained she couldn't do the dancing or the actions and Esme was too young to join in with the action on her own.

'I was just suddenly in this hugely embarrassing situation where, I didn't know what to do. And Esme didn't really want to sit on my knee throughout but she's too young to join in the actions on her own. So I found that people in the group were just coming and taking her off me and dancing around the room with her. ...I feel like she's just kind of being swallowed in to something I'm not really allowed to, I think people

are really trying to be helpful but it just isn't, and the whole thing is really awkward ... .. And I'm no, you're not having her. [laughing] That's it. And I glared at her something rotten. It's quite, surprising how strong your emotions can be in the midst of something like that.'

These emotions will be returned to in the next section when I will explore Lizzie's strategies for challenging the perceptions of others through creative strategies related to visible and invisible difference.

The most dramatic change in health, however, was for Amanda, who had been recently diagnosed with Sjogren's Syndrome - an autoimmune condition which can cause fatigue, muscle and joint pain. Reflecting back on the birth and the period of early motherhood Amanda returned to the 'shock' she described in her previous interview at the embodied challenges she faced. She framed her account of birth in retrospect in relation to her 'ignorance that a caesarean could be 'such an unpleasant experience.' Recalling our last interview she explained that she was probably still recovering from the birth and unknowingly the physical effects of the undiagnosed autoimmune disease. Her experience of her illness, particularly the period awaiting diagnosis is described as the factor that challenged her concept of herself as a strong person.

'It has been probably the most difficult thing ..I've never felt that low really ... .. more to do with myself rather than how I was looking after him... ..it came at the worse time... .. I just really felt physically so low, as well as emotionally... Emotionally it was just hell, I always sort of thought, you know you'd come through it but that was probably one time I really did feel, I don't think I can go on (.) how am I going to look after Ewan ... ..you have plans and they go out of the window.'

The shock of motherhood involved the physical challenges of dealing with a baby with colic (lifting, carrying, disrupted sleep) and her environment; carrying Ewan in and out of her top floor flat. Eighteen months after the birth Amanda described her relief as he was able to follow her around and 'amuse' himself although she tempered this with new physical challenges, explaining that it was an 'awkward age' as he ran off and had tantrums that she found difficult to manage. Things had improved for Amanda, however, with medical support. Her doctor had assured her following the diagnosis that her condition was not terminal and she found the medication prescribed gave her more energy. In addition, the new location and her support of her friend who had become her PA meant that she was given some respite outside the flat.

As was typical of Amanda's overall motif it was a fear of neglect and apparent invisibility that marked her relationship with social services.

'I mean people aren't mind readers and you do need to tell people if you need help. It was really hard to get the help of social services, you managed before so why can't you manage now? Shows their complete and utter cluelessness.'

Amanda attributed her capacity to cope emotionally with her ability to recognise her embodied limitations and claim social support:

'Because I think it is the one time in your life that you will realise that you're different from other people. Whether you want to accept that or not, then you know that's, your choice. If I didn't have the help don't know how I would have coped, I would have probably been a mother who was kind of pulling her hair out and probably suffering from postnatal depression ... .. I do consider myself as disabled now and that has been a long hard process.'

Like Cathy and Lizzie, Amanda's also appeared to have inspired her to increase her level of political participation in a disabled parents' organisation both through an online forum and attending local support meetings.

'I think there are so many people out there struggling to get help. You get loads and loads of responses people are like thank god someone's started a thread about this.'

Making use of the direct payment scheme Amanda had been able to arrange for her friend who was also a mother to act as her personal assistant. This enabled Amanda to make continued links with other mother's common experiences, suggesting that the support she received was emotional and social as well as physical. In addition, her personal assistant has diabetes enabling Amanda to draw on their common experience of physical challenges related to illness. Describing an incident in which Ewan had a tantrum on the floor of a supermarket she explained:

I was all flustered. She goes are you all right? And I said oh god what a nightmare, how embarrassing, you know, cos people walk around and they're looking at you. And things like that and she said to me, you know you will get used to it. That people do sort of look like that and I thought well it's not just me that gets it. Because immediately you think it's just because they think that I can't cope.'

Building on this confidence and recognizing the emotional pressures of parenting for all mothers, I noted a marked shift in the way in which Amanda was making her experience of disabled motherhood liveable. Moving beyond a desire to mark a similarity in experience with other (able-bodied) mothers Amanda went on to assert her capacity to parent despite her limitations as superior to those who appeared unable to interact with their children in the same way;

‘You go to these soft play areas, you see the parents sort of sit there and stare in to space going getting me out of this hell (laughing). Two hours of screaming kids, and you think they're not really interacting with their children either, so (laughing). At least I sort of stand there and cheer him on you know (laugh). Just really struggling with their children to keep control of them and they're emotionally very down. And then you realise that a lot of things that you think are exclusive to you, actually do affect all women. And, you know when actually you seem to be coping a lot better than a lot of other people really. That's quite an eye opener really.’

Amy's discussion of her son's development and her experience of visibility felt quite different. In this interview she focused on the process of building communication between them which had developed considerably since the previous interview. She reflected back on teaching her son to sign while also talking to him.

‘It was frustrating at first because I didn't always understand certain words he said. He got really frustrated with me but he would sign as well and it was the signing that helped me understand what he wanted.’

Amy's focus on her son's behaviour and communication can be put in context with some of the difficulty I felt in the previous interview to elicit an account after Jacob awoke from his nap. Drawing on this shared experience of the research process I encouraged Amy to reflect on the difficulty of communicating with others while she is with Jacob:

‘We don't have that capacity to think about what you're going to say, and don't have a baby to think about as well, it's just, it can get a bit tiring. ... I've got to think about what Jacob doing, and I'm trying to hear the sound that he's making to understand... what he's trying to say, so it's tiring.’

For Amy, it was returning to work full-time when Jacob was five months old that posed the greatest challenge. I was surprised when I heard that Amy had returned to work shortly after her second interview as she had claimed to be really enjoying being at home with her son and that work was no longer important. After her husband's redundancy the couple agreed she would need to apply for a job in a different city to help out financially. Her husband then got a new job shortly afterwards meaning that Jacob was put in full-time childcare with a child-minder. She explained she often found it difficult to understand people's thick accents (being from a different region) and she struggled with tiredness during the day which affected communication. After work she found it difficult to engage with her son's needs as the child-minder would ask her about her son's behaviour and communication.

'I wasn't with him during the day, I was feeling like I didn't know him anymore and I didn't know what to say to them.'

At this third interview, Amy explained that she had decided to finish her current post and would return to full-time mothering.

In contrast to the way in which the other participants balanced interaction with their child with the interview, Amy actively encouraged Jacob to explore and participate.

'Amy's facial expressions were generally enjoyment, delight and pride in her son. There was a lot of smiling and bending over into his face to read his facial expressions. Jacob was apparently observant of our facial expressions always looking up at our faces when we spoke. When I laughed at one point about something he laughed in a really engaging way, looking to both of us as if he was part of the adult conversation.'



This gave me an insight into the complexity of Amy's capacity for (social and embodied) autonomy as a deaf mother. It helped me understand why Amy appeared so consumed by attending to Jacob in the previous interview, and gave me a sense of how her demanding job might be incompatible with her perception of meeting her son's needs. In this interview I also learnt more about what Amy found 'daunting' in past interactions with others particularly in group settings, when she herself was not 'entirely comfortable' with her baby.

'I just found it really daunting just because I'd got this new baby that I'm not entirely comfortable with, meeting people that I didn't know. The fact that it will be noisy just made it really daunting.'

Amy talked positively about help and introductions from her health visitor when attending her local sure start community groups for mothers and babies and of her interactions with other mothers. By taking part in shared activity in the groups Amy explained she was able to be sociable with other mothers while also addressing Jacob's needs (without an emphasis on conversation). Attributing her enjoyment of these groups to her 'sociable' nature Amy described the way women supported her, moving to quiet spaces to ensure she was able to participate in conversation. The opportunity to interact and be with other mothers and their babies gave Amy an invaluable space for social autonomy which was seemingly denied through the challenges of combining work with motherhood. This moment also marked a turning point for Amy whereby by making visible her implant she experienced a sense of acceptance and understanding from (able-bodied) others, giving her the opportunity to reinstate the account of her identity that she presented in our first interview. As she explained:

'I found it easier if someone else tells them (referring to the introduction from her health visitor to the other mothers)... .. 'But, I always had my hair down

so I never had my implant on show because I think I just didn't want to be seen as different. But then I think I realised that I needed to make people aware and to remind them. It makes it easier if I have my hair up... .. They don't see me as a deaf mother, they just see me as a mother, accepting of the changes that they have to make, simple things like they know that if I need them to repeat something they will. I think because of that I don't, I don't see myself as a deaf mother, I just see myself as a Christian first because that's really important to me. But then, then I see myself as a mother ... .. if they had made more of an issue of my deafness then, then I think it would be different. But I'm just really pleased that I've made friends who just treat me as a normal mother. And don't make a fuss.'

Therefore, for all of my participants, these reflections on the first year of motherhood highlighted an awareness of the dramatic shift in their experience of embodied and social autonomy related to their child's development and for some, the parallel deterioration of their own physical and emotional health. In the process of accepting the limits to their autonomy and the need for increased support and assistance they had to broach the issue of in/visibility in their relationships with others, attempting to make these needs met without subjecting themselves to negative perceptions of disabled motherhood. The strategies my participants drew on to make this process more liveable, all reveal patterns of repeating, extending or developing their pre-existing ways of making sense of disability and motherhood. In some cases there was an apparent sense of resolution in this process settling some of the tension experienced in the past. Participation in disability politics and supporting other disabled parents appeared to offer some of my participants a channel for some of the 'determination' that characterised their earlier biographical accounts and for some, a way of resolving some of the tension that appeared to exist in relation to a sense of competence and

respectability (as implicitly classed) and negative conceptualisations disability. In addition, the acceptance, recognition and empathy of family, friends, services and professionals and/or shared experience with other able-bodied mothers played a significant part in their capacity to create a positive sense of self as disabled mothers. At this time it was clear that distinguishing what makes their experience different from that of able-bodied mothers was for some painful and shocking (as for Amanda and Magda). Yet reflecting on the challenges that all mothers face also enabled a sense of achievement related to their own strength and determination.

Despite marked acceptance and resolution in these accounts, it is still clear that this process of sense making is inherently fragile. Much is dependent on the support and recognition of others for their role as mothers and their specific needs. The experience of increased visibility, particularly in public settings, challenges the delicate work of making disabled motherhood livable. I turn now to the specific experience of Lizzie, who was unique in that unlike the other mothers at this time, she had moved to a new geographical area and had just begun to attend mother and toddler groups. For Lizzie every day interactions with members of the public appeared to reinstate some of her previous concerns related to the in/visibility of her disabled body. The interview encounter itself became a mirror for Lizzie's strategies for making sense of these experiences.

## **Section 2: Playing with the boundaries of visible and invisible difference**

This third interview with Lizzie was one that I anticipated with a certain element of dread. My encounters with Lizzie always felt challenging. As I outlined in the previous two chapters I would leave my interviews with her feeling guilty and responsible. After the first interview in which I found Lizzie pregnant and homeless I described a process of imagining myself in her position and reflecting on our similar class backgrounds.

As I presented in Chapter 4, a core theme within Lizzie's experience of being disabled was related to having an 'invisible' impairment. Indeed, as I have documented, this was the first challenge Lizzie presented in our initial encounter as she attempted to prove her eligibility to take part in the research as a disabled mother. Others have argued that the experience of invisible difference is significant in relation to concepts of 'passing' as individuals are faced with the question of whether they should make their embodied difference visible or keep it hidden from view (Sherry, 2004, p 773). For those disabled individuals who experience invisible embodied difference or are able to conceal their embodied difference there is potential for 'passing deliberately' or 'passing by default' (Samuel, 2003, p 235). As I have already discussed in previous chapters the concept of 'passing' has been used to demonstrate the management of a spoiled identity where discredited individuals 'conceal' their difference from others in their social interactions (Goffman, 1968, p 65).

Literature within the disability field on the 'passing' of impairment has highlighted a range of strategies that individuals draw on to conceal their impairment in different social contexts such as the use of clothing (Thomas, 1999). Therefore, it is significant that in contrast to the field notes made following my interviews with other participants, I made detailed descriptions of Lizzie's appearance. For example Lizzie had sent a link to her website in our initial email exchange which contained alongside snippets of her music, photos of Lizzie in various vintage outfits. In our first meeting Lizzie was dressed in a brightly colourful vintage kaftan that covered her bump and I described her arthritis as barely visible. In our second I described Lizzie's appearance as 'punk' with a striped rocker jumper accessorised with safety pins; in contrast, her daughter was dressed in a simple white baby grow.

By the third interview, however, I was startled when Lizzie opened the door dressed in a full Salwar Kameez, and traditional Indian earrings and bangles. This was particularly confusing as I had begun the process of analysing Lizzie's case, noting her reference to her 'dark skin' which she believed disguised her arthritis (providing her psoriasis was 'not playing up') as she looked tanned, well and healthy. I do not think I considered Lizzie to be Asian, but in this moment I had a split second of doubt. It is quite possible that Lizzie's choice of dress could reflect a conscious effort to conceal visual signs of her arthritis. At the time, however, I felt troubled, not understanding the particular message she appeared to be sending through her dress or what kind of response it required.

This troubling feeling stayed with me throughout the interview. Lizzie explained that she had moved to her local area on account of greater accessibility and facilities than would be available in the suburbs. With repeated reference to the 'ethnic clash' in the area, she articulated a conflicting sense of fitting in as 'someone with a problem' while remaining an outsider:

'It's a really poor area but you have also got this tremendous ethnic clash... ...  
... I am the only white mother in the group.... ... It just seems that everybody  
at that group has got some kind of problem of issue of whatever. So I fit right in  
really ... ... There was an argument between two of the mothers, which  
really made it a bad atmosphere cos it got like Jerry Springer. It really was going  
to kick off big time. I just tried to stay out of it.'

Lizzie suggested that her brown skin made her 'blend in' in with the local area explaining that while she was the only white woman in the group she has often experienced episodes in which she would be mistaken for Asian. According to Lizzie

this misrecognition often resulted in a sense of distance once her identity as a white person became apparent.

Lizzie: 'You just don't know how much of it is down to culture, or, I don't know. Cos I dress like this, I wear more Indian clothes than Indian people do. And I'm like fairly dark skinned. Nobody ever knows what my background is without asking me first. But sometimes I find Indian people really friendly to me until they realise that I'm not Indian and then that stops.'

Interviewer: 'So do you think maybe they thought you were Indian?'

Lizzie: 'I've got no idea, how would you ever know cos you can't talk about these things can you?'

The experience of not fitting in, or almost fitting in could account for Lizzie's appearance in the interview as she plays with the boundaries of visible and invisible difference, challenging others to identify her, questioning their similarity and difference from her own situation. Her dress challenged me into trying to understand or make sense of visual markers of a culture I do not belong to. In contrast, her seemingly-confident display of this dress appeared to suggest a form of insider knowledge specific to her particular geographical environment. I would suggest that this specific challenge echoes the way in previous interviews that Lizzie challenged me as a middle-class woman to identify with her position along class lines. It mirrors her account in the previous interview of the way in which her health visitor responded to her situation by identifying with her along class lines only to then be rejected in her interview account for failing to address Lizzie's specific needs. There appear to be moments of identification in her interactions with others followed by the experience of rejection.

This performance of visible and invisible difference stayed with me well after our interview. Shortly after leaving I described feeling 'false' despite our friendly exchange and my strong feelings of responsibility and identification with Lizzie in previous interviews. My own discomfort could be connected to Lizzie's attempt to make a connection with me and our common white ethnicity alongside social class in a particular context in which she feels out of place. Over the course of my analysis, however, I came to an alternative explanation, to which I now turn.

In this third interview, Lizzie also described what a male friend had said about a musician Ian Dury and the way in which the musician had dealt with prejudice by creatively altering his stick making it more aesthetically pleasing:

'He said he was an ugly cripple ...And that is how a lot of people think about disability. Unfortunately, it's ugly. But you know, Ian Dury decorated his walking stick with red and black stripes. So you don't have to just stick with it.'

Not having 'to stick' with other people's perceptions of physical beauty can be demonstrated through the altering of one's appearance. Again I would argue that Lizzie is not attempting to literally 'pass' as an Indian woman or deny her status as a disabled woman in relation to dominant social norms about the 'body beautiful' (Featherstone, 1991). As a process of challenging or queering difference, Lizzie's account mirrors the aesthetic project of 'disability chic' within the arts in which visible markers of disability and associations of 'shame' are exaggerated and made erotic (Magnet, 2012). Indeed, Lizzie may have chosen the particular dress for its bright colours, rich fabrics and adornment which stand out in the area in which she lives. In the same way that 'drag' is understood as deconstructing fixed categories of sex and gender it can be argued that Lizzie is deconstructing the cultural construction of disability as outside the realm of the 'body beautiful' (Butler, 1993; Featherstone, 1991, p 170).

My encounters with Lizzie thus demonstrate a different way of understanding 'passing' in relation to invisible difference. The distinction, however, is not clear cut. As in the case of Cathy's experience of 'passing', moments of claiming a common identity or experience and the possibility of concealing embodied difference highlight fragile emotions involved in her process of sense making. In the context of the 'underprivileged' environment in which she lives, however, the danger of misinterpretation is acute, drawing attention to the implications of working with limited resources and the disempowered role of the marginalised and abjected subject (Butler, 1993).

### **Section 3: Parallel body projects in the present**

I turn now to present my participants' accounts of the embodied and social development of their children. These discussions felt significant as they highlighted their hopes and fears for their children in the future as they grew up with a disabled mother. My participants' observations of their child's development were interwoven with accounts of their own embodied experience, as they struggled to maintain their own projects of relative autonomy.

As their children developed and became older my participants talked about their sense of their child's increasing awareness of their physical impairment and limitations. All talked about a sense of conflict between mother and child, captured in descriptions of children's agency such as 'being naughty', 'flinging (herself) around' and 'fighting' when having their nappies changed. Kirsty talked about 'a real battle of the wills' between her and her daughter. Yet they also reported moments of calm in which their children appear to 'intuitively' know about and adapt to their mother's impairment/physical limitations. As described earlier in this chapter Jacob had learnt to observe facial expressions from Amy's teaching. Others explained:



'He understands now something is not right and has begun helping me.'

(Magda) 'I think she realises now that I can't pick her up and she can't fling herself about...she is quite patient really.' (Cathy)

Magda and Cathy appeared to welcome the beginnings of a shared project of interdependency with their children. Yet for Amanda and Lizzie who were facing the possible degeneration of their conditions, this sense of knowing and adaptation on the part of their children provoked worry and negative emotions. For both participants this worry and guilt related to a sense of enforced embodied separation from their children as result of their own limitations in participating in activities.

'Maybe in a way he instinctively knows that there are certain things that he's going to have to do on his own, I don't know...oh you know I feel kind of bad about it.' (Amada)

'She is beginning to realise. That started with playgroup and that is the tip of a very large iceberg...I don't know how I am going to deal with it or how she is going to feel about things.' (Lizzie)

Despite these fears and assumed limitations, my participants' accounts demonstrated considerable enjoyment and investment in their children's physical, social and/or mental development. In many cases the way in which my participants accounted for their enjoyment appeared to speak back to their own experience of disability. The most obvious examples of this was the way in which they took pleasure in their child's physical strength and activity. Comparisons with other babies in her peer group resurfaced in Kirsty's account of her daughter;

'I mean she can build quite happily a tower of 8 or 9 bricks, high, both fine and gross motors, outstanding I don't know why. Neither Steve or I are particularly

[laughing] physical people. But you know take my hat off to her, she's done it in spite of us rather than with us. ... .... It's just because she's ahead of herself that I can feel quite (.) Okay about it. But it's down to her, not particularly anything I've done, its more her genetics'

By attributing her daughter's physical development to genetics, Kirsty apparently contradicts her statement made earlier in the interview that she planned to have her daughter walking and talking by the time her second child arrived. Indeed, this interview made me reflect on the noisy interactive toys that so perplexed and frustrated me in the previous interview. During this interview Kirsty kept the large television screen on playing nursery rhymes and broke off to play 'Row Your Boat' with her daughter something she professed to doing 'as much as 70 times a day.' Kirsty drew on her professional knowledge as a speech and language therapist to encourage her daughter's development, and appeared instrumental in encouraging and monitoring her motor skills and language.

It was also apparent, however, that this investment in her child's development brought home for Kirsty the relative neglect she felt she had received for her condition, as seen in this extract as her metaphoric 'ramp' led into a seemingly unrelated discussion of her own treatment:

'You often teach a child to do something before their age ... metaphorical ramps to help you through things. .... I don't give them a physical ramp to help them through but I give them a way to overcome something before it happens, so that it doesn't happen and I think that that's lacking in an awful lot of what happens with the treatment. And from what I've spoken to of other people with disabilities there doesn't seem to be any specialists in the area for maternity and you know you just go to a regular obstetrician. And you know (health visitor)

knows absolutely nothing about this condition....'

Amanda's son's active and independent character contrasted with her own deteriorating health and she revisited the language of shock to make sense of this in a similar way to her account of birth.

'He is full on all the time, and that's a shock really, cos it does affect you physically.'

Amanda explained that she made considerable effort to get out of the house with her PA's support and engage Ewan in activity. Like Kirsty she observed the difference in her own son's development from others, 'wondering' what it would be like to have a less active child.

'It is strange to see that I have such an active child when I have so much less ability from the other parents whose kids just kind of sit there. I sometimes wonder what that would be like to have a child like that

... ..

He is a very confident child and he's really outgoing and I want to keep him like that. I don't want to kind of, you know I don't want to be one of those people that's saying come here all the time. When he's older as well, when he has to do more with other people because I can't do things with him. You know I've accepted that. Luckily he loves people, you know, he's got no fear of people at all and it is only for the next year he will need me then he will be off with his friends playing at nursery.'

Amanda's account captures the process through which she came to terms with the relationship between her physical decline and her son's development. It is clear that Ewan's outgoing independence is something she admires echoing her own 'feisty

character' as a child. Ewan had not inherited her condition yet Amanda's anxious requests for her health visitor to measure his height revealed that he was in the low percentile. Drawing on her childhood experience and that of a 'short' friend Amanda explained:

'His dad is short and his uncles are short so he has lot of positive role models... hopefully you know for as long as I'm around and Richard's around he's going to have a completely different up bringing to what we had.'

While I have presented my participants' parallel body projects as a positive and celebrated occurrence within their accounts, it is notable that none of the children were themselves disabled. Amanda's fear of passing on her condition to her son speaks to existing research that has highlighted how medical discourses of risk can be particularly sharp for disabled mothers (McFarlane, 2004; Thomas, 1997). While Amanda's son did not inherit her condition, the focus on his 'small body' in her account and the way in which she makes sense of this in relation to alternative 'role models' and his different upbringing highlights a desire to promote a positive sense of self in relation to difference.

Lizzie's reflections on her daughter's healthy and beautiful body are less comfortable accentuating the way in which her experience of disability is framed as 'ugly'.

Following the deterioration in her health Lizzie had been given free hoists and chairs by NHS occupational therapists and she uses a mobility scooter while out (as part of shop mobility schemes). She described this equipment as 'ugly' and 'geriatric'. In an account of a shopping trip around the local mall Lizzie described the look on her mother's face as 'rattled' when Lizzie used the local shop-mobility (mobility scooters). Lizzie talked about her parents' difficulties in 'coming to terms' with the visible markers of her arthritis, in particular reflecting on her father's own fears.

'He, is terrified of getting old. He's terrified of mobility scooters and what not. It's his hang up .... he has got problems with having a child that has a disability. He's always keen to go on about how healthy and strong Esme is. So she's not like me.'

The challenge of living with visible psoriasis is something that can be traced across Lizzie's case. In the first interview she reflected on the experience of having psoriasis as a girl, commenting that girls are 'expected to be pretty'. In our second interview, Lizzie described an encounter in the baby clinic in which another mother changed seat when she caught sight of Lizzie's arms. Despite the repeated reference to the 'ugly' and 'geriatric' nature of disability, as I have presented above in this interview Lizzie's focus was on the colour of her skin and the way in which it enables her to 'blend' in to the environment in which she lives. She talked about her daughter's doll-like appearance as attracting admiring looks and comments from passers-by.

'And in this particular area she attracts so much attention. I blend in fine, I'm a brown person of indeterminate origin nobody knows, everybody says to her, that she looks like a little dolly ... .. oh my god. Is this going to happen forever? And yes it has. She looks like baby on the fairy liquid bottle. I think I mentioned last time I would have been quite happy to have a very plain dumpy brown baby and I've got a beautiful little blonde advert baby. That everybody else wants to give a good squeeze to.'

In all accounts of physical, mental and social development of their children, my participants placed emphasis on their (children's) capacity for autonomy and independence and highlighted the health, strength and attractiveness of their bodies. At a time in which they appeared to be coming to terms with their own embodied and social limitations, these accounts reveal considerable investment in their children's

parallel body projects. While this investment uncovers a sense of sadness, loss and fear, there is also a sense of great pleasure and enjoyment. These emotions were woven into the way in which my participants made sense of their experiences of disabled motherhood, reminding them of their difference from others but also emphasising the potential for achievement and success as they watch their children grow.

## Endings

It being our last interview my participants appeared to end their accounts of the first year with a sense of conclusion and reflection on their experience of disabled mothering. For Amanda, Amy and Cathy this involved an explicit reflection on their own perception of themselves as 'disabled' or 'deaf' in relation to others. Speaking back to their experience over the past year I got the impression they were imagining the readership of the thesis or its findings by other disabled parents. My participants talked about the lessons they had learnt with a view to help other disabled women.

I think probably the one thing I've taken from it is just go for it you know.

Don't allow people to tell you, you can't do anything and go out and get the help if you need it, because that does make a big influence on how you cope I think.

But it is very difficult for disabled mums to get help that's one thing.' (Amanda)

'If it can help someone else who you know, is hesitant to have children.'

(Magda)

My participants' concluding statements brought together the difficulties they had faced with a sense of triumph and achievement. For Kirsty's case the imagined readership is that of health professionals mirroring her theme of not only their responsibility but of the complex needs of disabled parents.

'Well I would like it to be read by health professionals.' (Kirsty)

At the end of the interview I took the opportunity to feed back what I felt had been key themes in the participants' case studies and where possible reflecting on some of the emotional dynamic. For example in the case of Amanda I reflected on her inclusion of myself as a short person in her comparisons with others, in the case of Kirsty I reflected on my particular position as a 'professional' visiting her home, in Cathy's case the challenge she made in our first interview and our reflections on the resemblance on her and her daughter. In Amy's case I reflected on the limitations in vocal communication in the interview and the importance of activity and visual cues, in Magda's case the realisation of how hard it had been for her and in Lizzie's case a reflection on our shared middle-class status and my feelings of guilt and responsibility on leaving. In all cases I reflected on the impact of listening to their accounts, of wanting to hear accounts of resilience and triumph and struggling to listen when reflecting on difficult times. I expressed my gratitude for their participation in particular their willingness to open up to me in what proved to be a challenging period in their life-course. This reflection appeared to provoke strong emotions in some of the encounters:

'No it is just I am welling up here. Someone from the website said that your emotional wellbeing is so important in pregnancy and thinking back it makes me sad to think I didn't have that. (Lizzie)'

'I said my impression of her was a very strong and determined person. Amanda was near tears. I think she is going to hug me but she doesn't. When I leave I feel satisfied but strangely again struggle to write up my notes. (3<sup>rd</sup> interview with Amanda)

## **Conclusion**

In this chapter, I have concluded my presentation of my participants' journeys into disabled motherhood. I have also concluded my illustration of the processes of the

emotional dynamic that unfolded over the course of the research. Central to this process has been the negotiation of embodied and emotional challenges as we reflected on the past.

By drawing together the six cases, I have highlighted cross-cutting themes and key moments within my participants' accounts in relation to the disruption, confirmation and re-making of my participants' body projects posed by motherhood. These projects relate to the pursuit of embodied autonomy and the acceptance of interdependency and assistance. My participants' accounts demonstrate the limits and possibilities for 'determination', be it embodied autonomy or the acceptance of interdependency in the context of in/visible bodies. My participants' imagining of the future offer fresh hopes through their children's parallel body projects, but they also hint at fears and their own feelings of loss.

It is, of course, a false ending. My participants' journeys into motherhood were only just beginning, and the challenges they had to face as yet unknown. My difficulty in leaving my participants such as Lizzie or my inability to engage with Amanda's experiences could again be seen as evidence of my defences against my own embodied fragility (in temporal terms) or my own sense of guilt and responsibility for my participants. Or conversely, as Walkerdine *et al* (2001) have argued, these emotions can reflect what the participant is unable to express herself.

In the next chapter, I will summarise significant 'turning points' as related to my participants' whole accounts of the embodied, life-course and relational experience evidenced in these three data chapters and the way in which my participants made these experiences intelligible. I will highlight the way in which the intersection of difference works through these processes.



## **Chapter 7**

### **Reflections on journeys into disabled motherhood**

In this chapter, I will reflect on the series of journeys into disabled motherhood and seek to answer my key research questions (detailed in Chapter 1). In section 1 I will summarise the findings related to the ‘body projects’ that occurred across the data, engaging with the processes of intelligibility that I argue characterised my participants’ individual accounts. In doing so I will address the question as to how difference intersects with these processes. I will then address the fragility of processes of intelligibility drawing out the emotional consequences of the quest to make a life liveable outside dominant cultural norms.

In section 2, I will evaluate the significance of my participants’ experience of embodiment (and emotions) for disability studies and disability politics with a focus on the relevance of the social model. I argue that the experience of disabled motherhood provides fresh insight into the experience of the body and its relevance for identity. I suggest ways in which my participants’ embodied (and emotional) experiences can contribute to a project of queering embodied norms with possibilities for the affirmation of a positive identity. Yet by paying attention to the limitations of this project in relation to the in/visibility of disabled maternal bodies and limited cultural resources I argue that there is still a place for the analysis and awareness of social barriers in women’s lives. Finally, I contend that emotions offer a point of connection across and within lines of difference with implications for a more inclusive disability politics.

In section 3 of this chapter, I will evaluate the importance of my particular version of qualitative longitudinal psycho-social methodology. Here I address the reader directly, suggesting ways in which they are drawn into following my participants’ journeys through the motifs of foresight and hindsight. I will locate my methodology in relation

to disability research arguing that a focus on the shared project of intelligibility provides a useful understanding of collaboration across lines of embodied difference. Finally, I will assess the limits and benefits of my methodology in relation to what is obscured and what is revealed through my attention to dynamic processes of intelligibility.

### **Section 1: Body projects, the intersection of difference, and the emotional implications of intelligibility**

Existing literature on disabled motherhood has tended to present key moments within women's experience of motherhood as significant for wider cultural constructions of disability (for example encounters with foetal scanning, the visibly-disabled pregnant body or the experience of maternity services in pregnancy or birth). While this analysis is valuable, we are left with a fairly one-dimensional understanding of the relationships between cultural construction or discursive practice and positioning and personal experience. Alternatively existing empirical research and personal accounts have tended to draw on women's biographical accounts of the past (in some cases following a significant passage of time) rather than 'walking alongside' them as they attempt to make sense of these key moments (Neale and Flowerdew, 2003, p 192). My research points to the value of understanding these key moments as connected within a process, mapping the way they correlate, overlap, merge and intersect.

By focusing on the way in which my participants attempted to make sense of their experiences of disability in the process of becoming a mother, I have been able to reveal significant insights into their capacity for agency in a period of dramatic biographical and embodied change. To summarise, in the first 'expectant' interviews my participants appeared to be negotiating available subject positions in relation to embodied social norms by presenting accounts of themselves as 'determined' and therefore eligible for motherhood. Medical professionals and family members played symbolic roles within

my participants' accounts, as enablers and controllers of embodied autonomy. These accounts were also characterised by classed and gendered ideas of success. The motif of 'determination' characterised discussions of romantic relationships, marriage and plans for a family extending findings from previous research (McFarlane, 2004; Prilleltensky, 2004; Olsen and Clarke, 2003).

Returning to Warren and Brewis (2004) analysis of the body, these body projects can be regarded as a strategy for 'cognitively dominating' their bodies, not in relation to diet and aesthetic presentation (although there is some evidence of this for example in Lizzie's pursuit of clear skin), but rather in relation to achieving social integration and autonomy through an exercise of mind over matter. Some participants also reported determined body project of fertility and conception. In these first interviews pregnancy can be understood as a 'body episode' or 'epiphany' where my participants' relationships with their bodies were altered (Warren and Brewis, 2004, p 221). The message conveyed was that they no longer had to work at it, evidenced through the sense of pleasure and amazement at their own fertility which appeared to defy their and other's expectations. It was at this point, however, that questions about the significance of difference came to the fore as my participants entered a 'common culture of mothering' (Thomson *et al*, 2011). Encounters with the pregnant bump, the anticipation of 'normal birth' and the future embodied challenges of caring for a young infant with limited support or assistance all provoked fears, frustrations and confusion in these 'expectant' interviews revealing the precariousness of my participants' situations. The challenge of disabled mothering became increasingly apparent in encounters with health professionals (such as the GP who advised Magda's husband she would be unable to cope with a disabled child) and the embodied experience of birth. Some of my participants managed these fears by engaging with equipment, expert knowledge and support within the family and personal assistance.

In Chapter 4, I mapped the way in which the motif of determination gave way to a sense of confusion, exposure and vulnerability. The physical experience of birth and, with it, the intensification of (dependent) relationships with medical professionals served as a rupture in the embodied experience of autonomy and (imagined) similarity with other non-disabled bodies. Birth forms a particular turning point within my participants' accounts, evidenced by the 'shock' that 'hung in the air' of the interviews. For some, this 'shock' was also articulated in relation to loss and acceptance. The experience of birth appeared to clarify any question about my participants' sense of difference or similarity with other women. The neglect of their particular needs led to the realisation of what was understood as discrimination and prejudice. The physical activity involved in caring for a child acted as another challenge to their sense of autonomy. Breast- and bottle-feeding appear to demand new 'body projects' with the possibility of challenging or elevating my participants' sense of embodied competence and autonomy in relation to other mothers. Encounters with medical professionals and the failings of equipment and environments all served to magnify my participants' feelings of in/visibility and the possibility of misrecognition in relation to embodied social norms mirroring findings in existing empirical research on disabled motherhood (McFarlane, 2004; Thomas, 1997).

In my participants' third interviews, documented in Chapter 6, I was struck by their creative re-working of disabled identities, how they were of framing their needs in relation to support and were engaged in parallel body projects with their children's development.

The unexpected challenges of my participants' deteriorating health and the new demands posed by a developing child support the findings of Olsen and Clarke (2003) that highlight long-term emotional effects of parenting with little or no support. My findings extend this research by demonstrating how the complexity of these demands

compound and magnify women's need for emotional support and assistance amounting for some to a crisis point and a new willingness to accept it. In accepting difference as a precursor to accessing support women must also engage with the perceived sense of abjection from embodied cultural norms, particularly in relation to encounters with other mothers and the general public, and health and social care professionals. My participants spoke back to this abjection in different and creative ways, building on themes from their previous accounts of determination, confusion and loss. At this point, I moved into the territory of understanding the processes of intelligibility engaged in by my participants, which includes improvisation and repetition in the forging of accounts of self that enable a liveable life.

For all of my participants, there was a sense of re-negotiating their understanding of self-determination. Being able to manage parenting tasks independently and creative ways of coping with these tasks was still articulated in relation to determination, particularly in the cases of Cathy, Magda, Lizzie and Kirsty. But there was also a sense of increasing acceptance in relation to their need for assistance and the interdependent nature of their relationships with others. Determination became as much about making their needs visible and normalising these needs in relation to the experiences of other mothers (disabled, infertile, those using a surrogate, able-bodied, single mothers).

Crucially, the prominent theme of neglect became more confidently assessed in relation to a lack of resources and understanding of their complex needs. Fears of being judged were reassessed in this context. For many, this realisation led to increased participation in disability politics and the seeking out of other disabled parents with experiences in common.

Confusion, particularly for Amanda and Magda in relation to their similarity with other women, translated to a greater certainty about what was common to all mothers and

what made them different. Recognising the limits to autonomy for all mothers and particularly the emotional toll of mothering enabled an understanding of the strength of their determination as evidence of their commitment to and success in motherhood. While a sense of loss was still acute across some of my participants' accounts, this loss was tempered with the sense of achievement and hope through the parallel body projects of their children.

For all of my participants, processes of intelligibility involved repeated questioning or querying the significance of embodied difference at moments of intense biographical and embodied disruption. It is here that the depth of the individual case studies can be really appreciated as I have captured the more unfinished, perplexing and improvised strategies that were used in the micro interaction of the interview encounter to make sense of difference over time. As I have argued in my presentation of Cathy and Lizzie's vignettes, these co-produced ways of sense making were provoked by strategies of what I have referred to as 'passing' (Butler, 1993). Rather than see Cathy's pleasure in the potential denial of embodied difference (as non-disabled or Jasmine's biological mother) or Lizzie's use of costume/dress as an attempt to disguise her appearance (as a white disabled) and pass as someone else (an Indian woman who fits with her local area) I have argued that what they provoke is a form of creative questioning that held both researcher and participant accountable. This process appears more akin to Butler's (1993) concept of passing, where a denial or exaggeration of difference is understood as a process of queering its significance.

### **Intersectionality**

My findings demonstrate that by paying attention to the way in which embodied 'situations' combined with my participants' personal histories we are afforded a more complex understanding of the way in which difference intersects with processes of

intelligibility (Rice, 2009; Yuval-Davis, 2006; Grosz 2004; p 20). As a sample of women who had previously had no formal or informal support or assistance (pre-pregnancy), the need to make their needs in pregnancy and motherhood intelligible became all the more marked in relation to their autonomous 'body projects' (Shilling, 1993; Featherstone, 1991). Reflecting the nature of my research sample (as predominantly white middle-class) it is not surprising that my participants' accounts were characterised by middle-class and hetero-normative ideas of the synchronicity of education, career, marriage and motherhood. This was particularly significant in relation to the way the temporal project of motherhood has been regarded as an expression of social location with arrival and departure points within women's journeys of social mobility (Thomson *et al*, 2011; Henderson *et al*, 2007; Byrne, 2006). Mirroring other work on the transition to motherhood I have suggested that aspects of 'determination', 'loss' and the fear of misrecognition all spoke to a particular middle-class version of self (Lawler, 2000).

The common culture of motherhood constructs women's transitions into motherhood in relation to 'choices' and 'synchronicity' in the life-course (related to career and relationships) presenting women with a chance of creating or making distinct maternal identities through engagement with cultural representations, expert advice and consumption practice (Thomson *et al*, 2011). Some of my participants' accounts illustrate how aspects of their classed biographies such as their professional knowledge and expertise spoke to 'expert advice' about birth and child development. Lizzie even used her class identity (as educated) to demonstrate her capacity to get what she wanted out of social services, asserting herself as difficult to 'fob off'. The majority of my participants had the economic capital to invest in baby equipment and resources. Yet as I have documented these strategies were not always successful with implications for the way they made sense of their experiences as disabled mothers, as Magda put it 'it just

brought home another thing I can't do'. My participants' accounts of community mother and toddler groups also highlight the way in which spaces of mothering generate distinctly classed (and racial) mothering practices, where the danger of misrecognition is more acutely felt (Byrne, 2006). There are limits, however, to what arguments can be made in relation to the intersection of class and disability related to the scale and limited diversity of my sample. Further research would benefit from drawing comparisons with the experiences of working class and non-white disabled mothers.

My participants' accounts also demonstrate the way in which the experience of the impaired and in/fertile body can have a bearing on the way in which they make sense of the transition to disabled motherhood. Fertility and the capacity to carry a child emerged as a prominent theme across the data set, where all of my participants with the exception of Amy feared or experienced some form of infertility. While this could be attributed to the difference between the experience of being a deaf mother as opposed to the experience of a physical impairment, it could also suggest that age was a prominent factor (Amy was the youngest mother of 26 years). The sense of wonderment and pride in relation to conception and pregnancy could have been heightened in relation to fears that they had left it too late mirroring other empirical studies on older mothers (Thomson *et al*, 2011). Cathy's experience of surrogacy and the associated interdependent relationship with the surrogate mother entailed an interweaving of complex processes of passing related to her belief that both were culturally unacceptable forms of maternal embodiment.

As I have documented, there was a marked difference in my participants' 'determined' accounts related to whether they experienced disability in childhood or in adulthood, with loss and acceptance forming key themes in the accounts of those participants who became disabled in adulthood. This difference had implications for the way in which the



motif of neglect was presented within my participants' accounts. Neglect related both to women's specific impairment needs and more generally to a form of social discrimination where attitudes, environments and equipment failed to meet their needs. For some of my participants neglect was not articulated in a negative way in their initial (pre-pregnancy) biographical accounts. Rather, (as was the case for example for Cathy and Magda) they appear to take some form of pleasure in the assertion that they were left to 'get on with things' as a child, and experienced a 'normal' childhood. Therefore, it is perhaps not surprising that visibility while expecting and in motherhood become core themes for these participants related to the possibilities of 'passing' difference and hiding emotional difficulties. In these cases particular crisis or turning points were revealed in their third interviews, both within a public space in which they were left to face their embodied limitations.

By paying attention to the common experiences across my participants' accounts - for example, the intersection of categories of gender, class and the experience of the body - it has been possible to draw out the complexity of their (similar) body projects in relation to dominant embodied norms.

### **The fragility of intelligibility**

It is important to acknowledge that women's agency in the context of existing outside embodied norms is inherently fragile. As my participants' encounters with medical and social care professionals and the medical and social care institutions more generally demonstrate, the in/visibility and potential abjection of disabled motherhood from social norms is deeply imbedded in wider discursive networks of power, which historically have been linked to intervention and judgement over women's capacity to parent (Thomas, 2007; McFarlane, 2004) For example it is only when Cathy is released from (real and imagined) surveillance from midwives, health visitors and social workers and

the adoption process following the surrogacy had been secured that we were able to comfortably reflect on the similarity in her appearance with her daughter in the final interview. That is to say that once the legitimacy of her status as mother had been confirmed (legally) we were able to comfortably play with the boundaries of embodied difference and similarity in our conversation.

Many of my participants' accounts make explicit reference to aspects of their emotional experience in the first year of motherhood, particularly in their final interviews, in which the passage of time and associated distance appeared to enable a time for reflection. Mirroring findings in previous research and personal accounts, I have documented the way my participants articulated emotions of 'shame', 'guilt' and fears related implicitly to their eligibility for motherhood and the danger that their children would be taken away from them (Wates and Jade, 1999; Thomas, 1997, p 632, Wates, 1997, Shakespeare *et al*, 1996, Morris, 1993). What is apparent is the considerable emotional work involved in making their lives liveable and moments or periods in which this became difficult or even impossible. Moreover, my participants' accounts of post-birth illness and the physical effects of coping with childcare tasks also revealed the way in which the embodied and emotional experience intersected. The experiences of Amanda, Kirsty and Lizzie in this regard all speak back to Thomas (2007) Olsen and Clarke (2003)'s arguments that illness and impairment should be considered as intermeshed with disability in relation to mental distress.

It is beyond the scope of this chapter and indeed this thesis to reflect on the relationship between the diagnosis of post-natal depression and disability. What Magda's experience does suggest, however, is that the repeated process of trying to make sense of her embodied experience outside of culturally recognisable norms of physical maternal competence and the accompanying fear of misrecognition can have emotional

consequences. As Mauthner (1999) argues, it is this sociological aspect that is largely neglected in the current definitions of postnatal depression:

‘...postpartum depression occurs when women are unable to experience, express and validate their feelings and needs within supportive, accepting and non-judgmental interpersonal relationships and cultural contexts’ (p 1).

Psycho-analytic commentary on disabled people’s experience of asking for psychological help highlights the way in which disabled people become locked into a ‘predicament’ where psychological help can confirm stereotypical ideas of their inability to cope. Yet, by denying or ignoring their emotional struggle, even as Watermeyer (2002) highlights by drawing on a social model that emphasises social factors (as opposed to impairment or emotional factors) both myself and Magda were in danger of rendering her experience into a ‘code of silence’ (Watermeyer, 2002, p 94). Key to this tension is the lack of discursive space available to disabled women in claiming emotional difficulties in motherhood.

## **Section 2: Embodiment (and emotions), theorising disability and politics**

In my presentation of my participants’ journeys, I have demonstrated the complex interweaving of social, embodied and emotional experience over time building on the feminist agenda within disability studies which has criticised the social model for failing to address the gendered and impaired experience of women’s bodies (Thomas 2007, 1999, 1997; Morris, 1996; Crow, 1996). I have done so in a way that presents the significance of the body and emotions without reducing this experience to coping with an impairment or illness. As a result, I hope to avoid reinstating the binaries between social model and medical model approaches, which as I have argued, have limited the scope of previous work on disabled motherhood. By focusing on what disabled women ‘do’ with their bodies I have demonstrated the way in which the body becomes

intermeshed with the making of identity as women attempt to make sense of their lives in relation to dominant norms. This approach has enabled a means of bringing in the experience of the body to the understanding of disabled motherhood that both complements and extends discussions of the intermeshed psycho -emotional effects of disablism and impairment (Thomas, 2007, 1999, 1997; Olsen and Clarke, 2003).

My argument follows that the experience of disabled motherhood provides fresh insight into the experience of the body and its relevance for identity. My participants' experiences show that the transition to motherhood entails an intensification of their relationships with their impaired bodies. This experience does mirror some of the concerns of existing (medical) literature, which has highlighted the physical demands of pregnancy, birth, and caring activities and practices. Indeed, my participants' experiences of conception, pregnancy, birth, feeding, nappy-changing, play and sleep deprivation all serve to highlight the sometimes unexpected capacities and limitations of their bodies. What is significant here, however, is how the experience and understanding of their bodies shifted from a sense that they are the drivers of their own autonomy to a realisation of the limitations to this autonomy in conception, pregnancy and motherhood, where support, assistance and the experience of inter-dependent relationships with others come to the fore. This process of realisation and acceptance, of reworking accounts of selves in relation to autonomy, and reconfiguring practices of interdependency is typical of all women (disabled and able-bodied) who undergo the transition to motherhood (Thomson *et al*, 2011; Hollway *et al*, 2008; Miller, 2005). But it is also particular to a group of (disabled) women whose embodied difference demands support.

### **Similar but different**

As I have documented in my account of the interview dynamic, my participants were engaged in continual conversations about their similarity with other women and the significance of their particular embodied difference. Significantly, while my participants appeared to come to terms with their limitations and need for assistance after birth, it is the shared experience of 'shock' and the emotional impact of 'coping' with the demands of a young infant that enabled them to assert a common experience with other women. Indeed, others have pointed to the way in which disabled maternal bodies disrupt dominant ideas about 'ideal motherhood' that all mothers fail to live up to (Malacrida, 2008). This analysis points to the illusion of the able body, in a sense we are all temporarily able-bodied and the idea of autonomy is an impossible modernist construction (Wilton, 2003; Marks, 1999; Shildrick and Price, 1996).

The transition to disabled motherhood can be seen as a productive space for 'queering' dominant norms related to the assumed naturalness and idealised version of 'able - bodies' (as independent and autonomous), drawing out their limitations and refiguring the disabled body as a place of 'becoming, reflection and production' (Goodley, 2011, p 158; Betterton, 2009).

As with the mothers in Malacrida's (2008) empirical study my participants (particularly in their final interview accounts) were able to positively present their capacity to cope (in spite of the social and embodied limitations they faced), and their children's parallel body projects. Coupled with an increasing recognition of the way in which neglect and a potential abjection from social norms exacerbated their physical and emotional difficulties some of my participants appeared to elevate their capacity to parent over and above able-bodied women who struggle. In this sense, my participants' processes of intelligibility reflect projects of affirmation' of a positive identity related to living with

impairment and celebrate their experience of diversity and difference (Shakespeare, 2006, p 69; Swain and French, 2000). Although concepts of autonomy and 'self-determination' remain embedded in my participants' processes of intelligibility, it is this presentation of 'embodied alternatives' that suggests not only a way of existing outside dominant norms but the potential to to unsettle and unstable their existence (Goodley, 2011, p 160). This celebration of identity in relation to their recognition of the interdependent nature of all relationships and the issues all mothers face in relation to support highlights the limitations with the social model, with its emphasis on autonomy and the separation of experience as the basis for identity (Gibson, 2006; Price and Shildrick, 1998). From a post-structural framework separation is an illusion as categories of difference are always 'provisional and insecure never entirely distinct' and it fails to recognises the fact of 'irreducible multiple differences' and connections that can be made with all others. (Gibson, 2006, p 189, Price and Shildrick, 1998, p 235).

### **Conceptualising interdependency and support**

Women's experiences of maternal embodiment speak to debates within disability studies surrounding the construction of 'interdependency', autonomy and assistance. The concept of 'carescapes' is significant here as my participants were also involved in organising and carrying out care work over time and in the process building relationships with their children and those around them, although this experience was restricted by the resources available to them. The concept of 'needscaapes' can also be interwoven as it highlights the way in which mothers need help and support at different points in the life-course (restricted by resources available) and how an interdependency of mutual needs can be on-going, proccessual and anticipatory (Watson et al, 2006, p 345).

Yet even within the family there is a sense of the limitations of concepts 'interdependency' when applied to the everyday context of caring for a young infant. Some of my participants like Kirsty, were able to draw on the interdependent nature of family relationships to make intelligible their need for support. But with the exception of Lizzie and the short period in which both Amanda and Amy's husbands were out of work (after the birth), all of the families had a fairly traditional set up in the first year of motherhood where the mothers stayed at home and fathers went out to work. Amanda drew attention to the oversight within social services who failed to recognise this connection when considering the need for formal personal assistance. In this context it is understandable that the offer of support for Kirsty's partner as a 'carer' was angrily rejected.

There was some evidence that my participants were beginning to consider ways in which their children could help them and adapt to their needs. Notably absent, however, was any discussion of the possibility that their children would be involved in caring for them in the future, although there is a sense that the possibility of this may be included in Lizzie's reference to the 'tip of the iceberg' in her daughter's process of understanding her mother's embodied limitations. This silence could suggest that the possibility is either unimaginable at this stage in the life-course or unspeakable in relation to my participants' processes of intelligibility.

Other participants revealed the need for formal arrangements of personal assistance which, (as I have documented), is both practical and emotional (see also Woodin, 2006 and Olsen and Clarke, 2003). The use of direct payments offered some of my participants a form of taking control, developing relationships which appear to recognise women's position as mothers while providing assistance to enable women a sense of autonomy in their everyday lives. Rather than overlay these formal

relationships with concepts of 'interdependency', however, what is needed is an understanding of processes of intelligibility in relation to dominant social norms. This process should enable, in practice, sensitive attention to ways in which concepts of embodied and social autonomy can be re-addressed in the context of motherhood. As others have argued, the application of concepts of 'autonomy' and 'interdependency' do not fully equate with the 'reality' of disabled people's experiences and what is needed is a pluralist approach to care and support which recognises the diversity of disabled people's lives and preferences, supporting individuals in appropriate ways (Shakespeare, 2006, p 151).

### **Seeking connections**

A politics based on the affirmation of a positive identity which does not deny embodiment and celebrates diversity contrasts with the social model where embodiment is denied (by separating out impairment from disability) and individuals are encouraged to seek equality with non-disabled people on the basis of their similarity (Shakespeare, 2006, p 80; Swain and French, 2000). But my participants' accounts also highlighted a repetition of the importance of acceptance by other mothers; this process was particularly pertinent in relation to women's experience of in/visibility. Indeed, many of the women coupled a sense of shared experience with other women with a sense of feeling supported. This was particularly pertinent in the case of Amy in light of the incompatibility of meeting the communication needs of herself and her son and her demanding job as a physiotherapist. The combination of this acceptance and the ability to focus on her son's activity in a public space saves Amy from potential isolation and associated abjection from embodied cultural norms. As my participants' accounts have documented, other mothers appear complicit in the project of co-constructing processes of intelligibility, from Amanda's personal assistant, Magda's NCT friends, and the



invisible support network of mothers available in internet forums. Indeed, as I have argued, the embodied challenges that all mothers face in the transition to motherhood demonstrate the temporality and fragility of all body projects (Thomson *et al*, 2011). The common experience of motherhood may well provide a lens for developing new ways of talking and thinking about emotional challenges, outside of dominant medical discourse without obscuring the particularities of women's experiences as disabled mothers.

### **Difference and divisions**

I have already outlined in the previous section the way in which aspects of difference intersected with my participants' processes of intelligibility in complex ways. Attention to this process is significant, as it provides a way of accounting for the complexity of women's experiences without resorting to a model that presents the layering of multiple forms of oppression (Begum, 1992). The difficulty of this complexity, however, relates to possibilities for divisions within and across groups of disabled women in relation to a collective political identity (Oliver, 1996).

In the past, others have argued that it is the neglect of impairment needs in the social model that serves to alienate particular groups of disabled people (Shakespeare, 2006; Olsen and Wates, 2003). Perhaps unsurprisingly, it was the issue of impairment that provoked discussion about my participants' embodied difference from other 'disabled' women. This was particularly pertinent for Kirsty, who resisted a shared disabled identity on the basis of highlighting her impairment specific needs for support. It is also striking that Amy's needs as a deaf mother appeared particularly complex in relation to the type of assistance that would be needed to enable her to balance work and childcare with the developing communication with her son. For these participants (who both turn to other (non-disabled) mothers for support and a sense of common experience), there

needs to be a social model that incorporates rather than ignores their experience of impairment, without resorting to some of the pathology of the medical model.

### **Queering maternal spaces and presenting ‘embodied alternatives’**

Throughout this thesis I have paid attention to the experience of the in/visible disabled maternal body. The disabled maternal body can be seen to ‘invade’ public (particularly reproductive) space, leaving them subject to the ‘stare’ or ‘forbidden looks’ (Thomas, 2007; McFarlane, 2004; Longhurst, 2001; Williams, 1997; Zitzelberger, 2005). My participants’ accounts of their interactions with health and social care professionals and my descriptions of the interview encounter within the interview also reveal the way in which the presentation of ‘embodied alternatives’ as new methods of coping autonomously can provoke confusion in the eye of the beholder and tension in the emotional dynamic (Goodley, 2011, p 160). I have argued that it is this paradox of invisibility that captures the wider picture of how disabled bodies stand in direct tension with normative constructions of agentic, autonomous, healthy and desirable reproduction in relation to fertility, birth and motherhood and the more recent display and celebration of the ‘pregnant beautiful’ body (Tyler, 2008). Others have argued that it is this provocative presence of the disabled maternal body that provokes a project of queering or defamiliarising what counts as nature and destabilising gendered and sexual norms (Betterton, 2009, p 84). By shifting a focus from idealised heteronormative forms of parenting based on biological conception and pregnancy (as opposed to surrogacy), natural and normal embodied forms of caring and ‘pregnant beautiful’ the disabled body can make connections with the agenda of queer politics (Reynolds, 2002). This may be the case, but whilst it is important to celebrate the potential of disabled maternal bodies to present ‘embodied alternatives’ my participants’ accounts have revealed the

emotional difficulties in relation to the continuous presentation of oneself as 'bold, brave and beautiful' as an individual project (Goodley, 2011, p 160; Cooke, 2005, p 10).

### **Social barriers and a political identity**

While there are implicit tensions related to the production of binaries within the social model, my participants' experiences of in/visibility and the failings of environments, baby equipment, services and relationships with professionals should be seen as complementing the general agenda of the social model with its emphasis on social and environmental barriers. Both a universal one size fits all approach to maternity care based on language of choice and equality and one which appears to label 'disabled women as a disadvantaged group ('ticking the boxes') appeared to jar with my participants' understanding of their own needs for support. On a very basic level, these needs relate to the physical and emotional challenges of impairment, illness, birth pregnancy and early mothering activity. My participants' accounts signify relative neglect of these factors ranging from slow diagnosis or failure to administer medication, a failure to provide adequate and appropriate care, equipment and facilities for birthing and a lack of support for individual needs (particularly in relation to adaptive equipment) for breastfeeding, winding, lifting, carrying etc. (see also Clarke, 2009; Olsen and Clarke, 2003; Thomas, 1997). These experiences mirror the arguments made by Thomas of the failure of services to address women's needs and the negative impact on disabled women's emotional wellbeing (1997). The services my participants used also appeared to neglect the temporal nature of disability and parenthood. Both Lizzie's experience of the lack of joined-up family and child services and Amanda's initial rejection from access to personal assistance based on her independence pre-pregnancy demonstrate a complete lack of understanding of disabled parents' needs, mirroring existing policy research (Morris and Wates 2006; Olsen and Clarke, 2003). These

approaches entail the risk of rendering women isolated, with an acute sense of abjection from social norms, the implication being that disabled people do not become parents.

As I have presented, for some of the participants in my study, it is an awareness of this neglect that enables a sense of collective identity with other disabled mothers. It is incredibly powerful that the transition to motherhood entailed new or increased political participation for many of my participants and in some cases a marked process of what others have referred to as a process of 'coming out' as a disabled person (Sherry, 2004). This complements the agenda of the disability movement and reflects research and personal accounts which have emphasised the importance of an understanding of social barriers for a project of resistance and positive identity (McFarlane 2004; Marks, 1999; Thomas, 1997; Finger, 1990).

### **Emotions and the social model**

Crucially, it is the fragility of my participants' processes of intelligibility that should form the central element of any model of disability or disability politics. Emotions, as I have presented, are the key link that brings together our understanding of the way in which the social and the embodied are intertwined (Thomas, 2007; Grosz, 2004). My participants' accounts and attention to the emotional dynamic within the interview encounters has revealed the emotional tensions inherent in their body projects and the desire to be considered like everybody else. What is needed within disability politics is the development of cultural resources that provide ways of talking about the emotional difficulty of embodiment in the context of living in direct tension with dominant social norms (Watermeyer, 2002). Whether this is a project that engages with medical discourse (for example the construction of postnatal depression) is a complex question related to the processes of power that weave through discursive practice and appear to be entrenched in the structures of medical and social care institutions.

The emotional difficulties I experienced as a 'curious observer' highlights the limited discursive space and cultural resources available for non-disabled or temporarily-able people in relation to the observation of the disabled maternal body. Shakespeare (2006) has argued the divisions within the social model between disabled and non-disabled people in relation to oppression fails to take into account other more positive dimensions of relationships. I would also add that this division obscures possibilities for a productive space in which the experience of embodied difference can be explored and deconstructed through the lens of emotions. This has potential not only for disability politics but as a means of improving relationships with health and social care professionals.

It is imaginable that the difficult emotions provoked in encounters with the disabled maternal body become even more powerful and complex for those professionals working within medical and social institutions. I have attempted to capture through women's accounts of interactions with others, particularly health and social care professionals, as awkward, tense and 'panicked' alongside my own field notes some of the difficult emotions involved in encounters at this time. I suggest that these difficulties relate to deeper psycho-social processes in which the disabled body represents repressed fears and anxiety, not simply for the individuals involved but as inherent in social structure and discourse (Lucey, 2004). There is, of course, no way of knowing what the midwives, health visitors and social workers were actually thinking or feeling during these encounters. Neither can we fully equate my own emotions during the encounter as a social researcher with those of health and social care professionals whose direct role was to assist, assess and/or inform women, a point I return to in the next section. But there is the possibility that attention to emotional data can provoke dialogue between research and practice. This was apparent in my presentation of Cathy's case-study to an audience of (social care) professionals who worked directly with disabled parents at an

ECRC Disabled Parenting Seminar (Hadfield, 2008c). Among the comments given, audience participants talked about their feelings of discomfort and guilt assessing the homes of disabled parents (when they themselves lived in 'messy' homes) and feelings that disabled parents were holding things back. There is the danger that a wish to avoid social embarrassment, to reassure the disabled mother of her capacity to cope and a denial or avoidance/inability to see difficulties results in the emotional vulnerability of the mother. As discussed in the previous section, despite demonstrative agency to manage these experiences, the emotional implications of such neglect must not be underestimated. Women's experiences point to a significant need for greater reflexivity and increased understanding of the complexity of needs, the capacity for neglect and processes of intelligibility in health and social care practice and education.

In summary, by moving from an approach that centres on investments in discourse positions, to what people 'do', it is possible to highlight new possibilities and creative ways in which disabled women attempt to make a liveable life outside the norm. I have attempted to present my participants' understandings of 'disability' on their own terms (Watson, 2002). By framing disability and mothering as a series of practices or body projects, it is possible to sidestep the limited possibilities for resistance that exist in positioning in political (social/minority model) discourse. My participants were able to create on a micro scale ways and means of negotiating their position in troubling relationship to embodied norms. This can be said to reflect ongoing projects of 'queering' difference and related affirmation of a positive identity. The challenges my participants present open up further channels of debate about the significance of difference and what experience can be held in common with others, through the lens of the maternal body. But my participants' processes of intelligibility were fraught with contradictions and tensions and are inherently fragile, limited by the available cultural resources that they can draw on. It is this fragility in the context of the in/visibility of

disabled motherhood that reiterates the importance of the 'social barriers' message of the social model and its importance for a political disabled identity. Emotions offer a point of connection across and within lines of difference with implications for a more inclusive disability politics. Further, they can provide significant insight for and dialogue with social and health care practice.

### **Section 3: Reflections on methodology**

My approach to my participants' subjective experiences of disability and becoming a mother over time does not generalise or make universal claims about either disability or motherhood. On the contrary, I have used process and subjectivity as particular tools, or as means of emphasising the complexity and diversity of our experience and understanding of disabled motherhood. The knowledge produced from this study is both situated in relation to a particular time and place and partial, emerging from my participants' accounts and the emotional dynamic. And yet, by 'walking alongside' the six participants in the study, I have been able to reveal the particular intensity and density of data that qualitative longitudinal research (QLR) affords (Neale and Flowerdew, 2003, p 192).

### **Reflections on a qualitative longitudinal approach**

In the previous three data chapters, I accumulated descriptive data for the reader. Taken as standalone encounters, this data illustrates the challenges women encounter in relation to their subjective experience of disabled motherhood at particular moments in time. Particular themes in my participants' accounts and aspects of the emotional dynamic have enabled cross-cutting comparisons to be made. As described in the second section of this chapter, we have seen the way in which particular turning points and defining moments can be mapped across my participants' experiences. These moments are key for contributing to our understanding not only of the way in which

disabled motherhood is constructed in society as a whole, but also for the way in which it can be experienced. They map onto existing findings from empirical research about disability and motherhood.

It has also been possible, however, for the reader to build a sense of each individual participant's story over the course of the first year of motherhood, both through snippets of my participants' accounts in the main body of the chapters and through the condensed case-studies which I have organised around the theme of invisibility. Presented with my data in a linear fashion, readers may have found themselves anticipating future challenges with an element of foresight, possibly mirroring the fears or hopes of researcher or participant. Reflecting back on previous chapters, a reader may have also experienced a sense of hindsight enabling a more complex understanding of my participants' experiences in the present. Particular moments in this process have marked subjective turning points. The condensed case-studies at the end of each chapter have been organised in relation to particular challenges felt by the researcher. In my encounter with Cathy, it was her initial challenge to reflect on her impaired body that felt the most compelling in relation to her experience of visible difference. As we have seen in the moment, these challenges - although experienced by myself as uncomfortable - were not always understood. With Magda I struggled to engage with her experience in the second encounter and it was only through her reflections one year on that this made any sense. In my final encounter with Lizzie I felt able to make sense of difficulties in the previous two encounters in building on my increasing understanding of her situation and experience.

The point of revealing this process is not to take the reader back and forth, mapping points of clarity and confusion, like a Spirograph, for the sake of producing a complex picture. Rather, the process produces insight into the particular experience of disabled



motherhood. Indeed, any confusion or frustration felt by the researcher or the reader in this process could be seen to mirror the experience of the participant; Amanda's explicit articulation of her feelings of 'confusion' is one such example. Insight into the way in which women make their experiences intelligible or are able to exist in a troubling relationship with the norm are revealed through this process.

By encouraging disabled mothers to reflect back on their own biographies and the past, their experiences in the present, and prospective feelings about the future, it is possible to avoid the dangers of reproducing flat, static, linear concepts of identity formation and development by showing the way in which identities are formed through a recursive, shifting and uneven process (McLeod, 2003; Bjerrum Nielsen, 1996). Embodied experiences over time inevitably become woven into this process where both reflection (of what the body once was) and projection (of what it could be) complicate the present subjective experience and the construction of identity in relation to disabled motherhood. As McLeod and Thomson (2009) argue, while it can be necessary for analytic purposes to separate the past, present and future, in subjective terms they are inseparable and constitutive of the temporal flow, whereby past and future are always apprehended in the present through free association narrative interviewing, observation in the 'here and now', and attention to the emotional dynamic produced in the interview encounter and beyond. In this sense, my methodological approach seeks to capture the reflexive process of the making of self. Moreover, a longitudinal methodology helps uncover how processes of intelligibility work involving repetition and adaptation for both participant and researcher.

The purpose of including my own subjectivity in the data collection and analysis was to portray the way in which processes of intelligibility are co-constructed or happen in unison. In this sense, the combination of process and subjectivity as analytical tools

enable a revelation of the psycho-social construction of disability and of disabled motherhood. The reader's own feelings of confusion, resistance, frustration, relief and other such emotions inevitable lend another layer to this process. Reaching the final data chapter, or indeed the analytic and conceptual conclusions of this discussion chapter, may appear to offer the participant, researcher and reader a sense of conclusion on my participants' experiences of disabled motherhood. In reality, however, this sense of conclusion is an illusion as the process continues.

### **Locating my methodology in relation to disability research**

In Chapter 3, I located my research design and method in relation to debates within disability studies about the role of the non-disabled researcher in the production of knowledge about disabled people's lives. Rather than accept the rationale that my difference as a non-disabled researcher would stifle or obscure an attempt to produce truths about disabled motherhood, I have argued that a longitudinal psycho-social methodology enables an interrogation of the co-construction of disability and the experience of disabled motherhood. Recognising the contextual nature of the production of knowledge, the previous three data chapters have presented my (often exposing) field note data and interpretations. I have been able to draw out the context of difference in each encounter and the way in which this was negotiated in relation to understandings of disability and experiences of disabled motherhood. By mapping this experience over time, I have been able to demonstrate how the partial knowledge produced from each emotional encounter could be pieced together in context with my participants' case studies. While interviewer and participant embarked on their own journeys in relation to understanding the construction of disabled motherhood, an examination of the emotional dynamic highlighted the way in which both through the literal encounter and the construction of my participants' accounts became a shared endeavour, or a shared

project of intelligibility. It is a focus on this process that gives us a more useful understanding of collaboration across lines of embodied difference than perhaps the more literal understanding afforded in emancipatory disability research (Zarb, 1997, p 52; Oliver, 1992).

While the power of interpretation, analysis and writing ultimately lies in the hands of the researcher, attention to emotions in the research dynamic can not only offer a sense of 'honesty' about the context of research but lead to a more insightful production of knowledge (Tregaskis and Goodley, 2006). By this, I mean that both participant and researcher are left much more open to interpretation than a straight textual analysis. In the process, participants are not just research objects; they become research subjects with the capacity to provoke great identification and empathy. Incidentally, the inclusion of researcher emotions also has the potential to pose questions, debate, and even identification and empathy, about encounters with difference.

### **Gaps and tensions within my analysis**

There are significant gaps, however, in my analysis related to my close adherence to the principles of the free association narrative in the early stages of this research (Hollway and Jefferson, 2000). These gaps relate to the principles of interrogating narrative as a means of eliciting evidence of unconscious processes, as opposed to a narrative analysis in a traditional sense that pays attention to narrative form, voice, repetitions and motifs. Indeed, I am reminded of Walkerdine *et al* (2001) statement that the account of the emotional dynamic should be regarded as a 'story amongst stories' and, as a result, one that should also be deconstructed (as I feel I have shown) (p 88). I do not think that this has taken anything away from my findings; indeed, I think my 'story' of the research encounters with my participants has provided a rich layer of data that has contributed to my analysis. Further attention to this thesis through the lens of traditional narrative

analysis, however, would contribute a more in-depth analysis of the way in which women construct their narratives and in the process deconstruct difference. As others have argued, this would provide us with a greater sense of agency, something I dismissed in the early stages of my research (Thomas, 1997). The shift in my participants' accounts from the carefully worked out 'determined' accounts while expecting, the confusion shock and difficulty in producing accounts that reflect this determination after birth and the way in which this was re-drawn, reworked and re-narrated in subsequent interviews reflect the finding of existing research (Miller, 2005, p 110). Future work on disabled motherhood could build on this analysis presenting narrative as something that incorporates gazes, places and spaces.

This brings me to the inherent tension within my work's attempt to combine Butler's particular version of post-structuralism with my own interest to retain an emphasis on the lived emotional and material (embodied) experience. This tension relates to the fact that, as Butler argues, the body is only accessible (that is thought, spoken or written about) through language. I find myself coming full circle with this debate. While I started the research relatively optimistic that my attention to temporality and emotions would provide me with a rich picture of my participants' experience of the body akin to Grosz (1994) concept of the 'Möbius strip', there is no getting away from the fact that I have ultimately presented a (shared) account of the experience of disabled motherhood. It is impossible for the reader to experience some of the pain, fatigue, immobility, and general physical awkwardness that impairment, illness pregnancy, birth and early motherhood can entail. While attention to the emotional dynamic surrounding my interviews with my participants provides a sense of the experience of disability, it is again only a 'story amongst stories' (Walkerdine *et al*, 2001, p 88) Nevertheless, stories and accounts have the power to evoke sensibilities in others, and this process is

implicitly temporal and relational as we draw on our embodied experiences in the past or contemplate future embodied events that are currently unforeseeable.

### **Locating my research in relation to psycho-social studies and QLR**

Positioning my research within the field of psycho-social studies has perhaps been the most challenging throughout the research process. As I alluded to in Chapter 4, the practice of letting go of clinical terms such as anxiety, desire, splitting, projection, transference and counter-transference in both my analysis and writing has been difficult. It is quite possible to re-address my analysis and presentation of the case studies in this way. For example, it is all too clear that the emotions felt upon leaving my interviews could have been articulated in relation to clinical concepts of anxiety and transference. Returning to the data, I could have explicitly explored my feelings of confusion, frustration, avoidance and further guilt and depression in relation to these concepts, suggesting that the anxiety provoked in this period could have lead a 'transference' of these difficult feelings onto the researcher. Instead, I have preferred to rely on a more descriptive means of presenting 'analytical transference' without getting tied down by the technicalities of psychological processes. That is not to let go of the 'psychic reality' of the research encounter, but to treat it differently to a clinical consultation and in the process 'make strange' the knowledge base we take for granted (Clarke and Hoggett, 2009; Baraitser, 2008b, p 426).

The way in which the researcher encounters were experienced demonstrates the deeply relational nature of my participants' experiences of the transition to motherhood and the way in which processes of intelligibility are always constructed in conversation with other able bodies (Butler, 2004). As discussed in the last section of this chapter, I could have been more explicit about what role or relationship I evoked for the participant in our encounter. Most notably, my participants' relationships with their mothers featured

heavily in their accounts particularly in childhood. My participants' accounts of their body projects incorporated the investment of their own mothers in childhood (and adulthood, in Kirsty's case), the assistance of others (medical professionals and social care professionals) in conception, pregnancy, birth and beyond, and a parallel project with their own children's embodied and social development. I have tended to avoid a psycho-analytic framing of the research encounter that presents my own emotions in relation to a possible transference of relationships with these key figures within women's accounts, although inevitably they form a silent presence in what can be regarded as the emotional conversation. It could be argued, for instance, that some of the difficult and challenging emotions in my interview with Lizzie lay cause to her difficult relationship with her family who apparently refused to accept her arthritis.

Rather, I have preferred to focus on the experience of in/visible bodies in public and private space, using the encounter and my position as a 'curious observer' to my participants' bodies and mothering practices or activities at the three different stages of expecting, four months after birth and one year after birth. This process has enabled me to speak back to concepts of the 'stare' and the forbidden gaze' that others have argued are so prominent in the experience of different bodies (Thomas, 2007; Zitzelberger, 2005; McFarlane, 2004; Williams, 1997). In doing so I have drawn out the way in which both researcher and researched were involved in a process of co-constructing intelligibility, seeking to answer difficult questions about the significance of difference and possibilities for a shared or common experience and understanding.

At a particular stage in the research journey, I became fixated on my role as a professional and whether my intrusion into the domestic space following the birth meant I experienced a particular transference in relation to my participants' experiences of being under surveillance by health professionals. In my final interview with Kirsty, I

went as far as to check out how she had experienced my presence in the interviews and whether she had considered it as similar to that of the health visitors and midwives she encountered.

Kirsty: 'No I don't really see you as a professional. Well you are a professional, but not like that. You are not here to help me. You are here to listen ... ..'

Interviewer: 'I felt that the core theme of your story was that you just wanted people to really understand what it had been like for you.'

Kirsty: 'Yes, yes that is it. I had never really thought of it like that but that is it. I want people to know what it is like, what it has been like for me. In saying that I would like health professionals to read it.'

This short piece of dialogue sums up the complexity afforded by psycho-social QLR methods. While interrogating my own position in the emotional dynamic (the transference of key figures) enabled me to imagine the effects of observation and surveillance on the participants in the study, the research process enabled a space for processes of intelligibility to be investigated. That is the way in which both participant and researcher strive to make women's experiences liveable (both for themselves and in some cases for the other). Rather than try and recreate clinical settings and draw on clinical language, I have found it more effective and indeed valuable to present analytic transference in this context. It is for this reason that I have repeatedly referred to difficult moments within the emotional encounter as 'challenges'. By doing so, we are reminded of the struggle the women are faced with in context with social norms surrounding disability and disabled motherhood. Yet it also neatly captures the way in which this experience plays out within the emotional dynamic capturing some of the work involved in making disabled motherhood liveable and in the process the potential deconstruction or 'queering' of embodied norms (Goodley, 2011). In doing so, I have

presented the way in which an understanding of the emotional dynamic within the interview can help us move beyond a preoccupation with 'internalised oppression' (emotional effects) towards an understanding about the conditions of disablement and the possibilities and limitations for agency and resistance (Tregaskis and Goodley, 2006, Marks, 1999).

This project has been very much an experiment on my part. In retrospect, it has made the presentation of my work, particularly in public setting, nerve-wracking but analytically valuable. Participation in psycho-social research networks and the support of my supervisors and colleagues sympathetic to psycho-social approaches gave me the confidence to analyse difficult moments in this process without internalising them. Nevertheless, as I have discussed elsewhere, the inclusion of subjectivity leaves the researcher relatively exposed, both professionally and personally (Hadfield, 2010, see also Elliott *et al*, 2011). In addition, as discussed in Chapter 3, a QLR approach exposes the participant and leaves them much more vulnerable to emotional harm on the one hand and limits the possibilities for anonymisation and confidentiality.

I have continually asked myself throughout the research process whether I would persist with this approach in future research for these reasons and whether it is valid as a blueprint for other studies. I am reminded of the considerable amount of resources that are required to do this well. In particular, I would advise the need for support and space for reflection throughout the research process. Working as a team offers one means of doing this creatively, as I have experienced with the MoMM project. But it is also possible to draw on professional channels of analysis (psychotherapy) to reveal what may be hidden from the researcher (Elliott *et al*, 2011). At the planning stage, research projects would need to give considerable weight to the analytical process, which is time-consuming and thus costly. The potential cost of personal exposure, both



professional and personally, to the researcher and participant must also be taken into consideration during the planning stages (Elliot, 2010). Nevertheless, QLR research offers valuable data that can enrich and challenge current understandings of individuals' lives.

## **Conclusion**

In this chapter, I have joined up the dots between and across my participants' accounts and the emotional dynamic revealed in the meeting between interviewer and interviewee. In doing so, I have captured the importance of process and the emotional dynamic in our understanding of the experience of disability and becoming a mother. By drawing attention to the work that women do in the transition to motherhood, when faced with a potential abjection from dominant social norms of embodiment, I have highlighted the experience of agency in relation to the limitations and possibilities for resistance in relation to the project of deconstructing difference. As I have argued, these possibilities and limitations have implications for disability politics and social and healthcare policy and practice, particularly in relation to women's experience of emotions. Moreover, this study can contribute to the shift within disability studies towards a more complex model of disability that is relational, social, emotional and embodied. Finally, I have evaluated the importance of my particular version of QLR psycho-social methodology emphasising the importance of my approach for disability research that works in collaboration across lines of temporary difference. Drawing together the strengths and limitations of my approach, I argue that it is the presentation of processes of intelligibility through a temporal and relational lens that gives us a more complex picture and clearer insight into the experience of becoming a disabled mother. In the next and final chapter, I will summarise the structure of this thesis and reflect on key absences, with a view for future research and investigation.

## **Chapter 8**

### **Lessons learned and looking to the future**

In this short chapter, I will conclude the journey of the thesis, reflecting on the lessons learnt and looking to the future. I begin by giving a brief review of the structure of the thesis, highlighting the key messages of each chapter. I will then go on to reiterate the contribution my thesis makes to knowledge within the field of disability studies, disability politics, and the increasing body of literature and research that combines qualitative longitudinal research with psychoanalytically-informed methods. I will then highlight future avenues and directions for future outputs and further research. Finally, I will address the passage of historical and biographical time since the research data was collected, analysed and written. I argue that the current political climate has magnified the key concerns that have emerged for this thesis and the need for a shared sense of accountability to make visible disabled women's struggle with the norm and the consequences of this struggle.

#### **Review of the structure of thesis**

In Chapter 1, I began the journey into disabled motherhood by contextualising the origins of the thesis in relation to personal and political journeys of making sense of disability. I outlined the key aims and objectives of the research and presented disabled motherhood as a key site for understanding the linked processes of temporality, embodiment and identity.. In Chapter 2, I located my study within the existing literature on disabled motherhood, highlighting significant gaps in relation to women's identity, such as the importance of temporality, embodiment and possibilities for agency and resistance. In Chapter 3, I mapped my research journey from my research design and methodology to my approach to analysis and writing. In Chapters 4, 5 and 6, I presented women's journeys into motherhood from the point of expecting a child to one year after

birth. In the process, I drew out cross-cutting themes related to key moments in women's accounts of past, present and future documenting the ongoing identity work of sense making relating to their sense of self as similar or different from others. In each chapter, the motif of visibility was also used to prise open patterns of intelligibility within individual case studies. Finally, in Chapter 7, I synthesised my participants' accounts and evidence arising from the interview dynamic, capturing the significance of process and emotionality for an understanding of the experience of disability in the process of becoming a mother. I evaluated the significance of women's embodied experience for disability studies and disability politics, arguing that the maternal body provides a productive lens for interrogating the importance of embodiment. Finally, I evaluated my methodology, highlighting the potential of QLR that draws on psycho-social insights as a means of making the complexity of women's experiences apparent (but with some limitations).

### **Contribution to existing literature and research**

My study makes a significant contribution to current debate within disability politics about identity. Through the lens of the transition to motherhood, I have demonstrated the significance of temporality, emotions and embodiment for our understanding of the lived experience of disability. By locating my research in relation to the turn in disability studies towards complexity I have demonstrated a fresh approach to understanding and investigating identity practices that can be made in conversation with disability politics. Central to this contribution is an examination of the way in which women 'do' identity in the transition to motherhood and in the process the way in which they deconstruct the significance of difference. I have argued that disability politics needs to address the limitations of these processes and the support and structures that need to be in place to support women. Empirically, my study contributes to the small

body of research and literature on disabled motherhood, identity and gender, providing a unique temporal perspective. It also makes a contribution to the increasing body of longitudinal research that is being conducted in the UK about personal lives and relationships.

I believe my study is the only study on disabled motherhood within disability studies that draws on the importance of temporality, embodiment, emotions and subjectivity. It also contributes to the increasing body of literature in the field that takes seriously the importance of psycho-social constructions of disability (Goodley, 2011; Thomas, 2007; Marks, 1999). An important difference, however, in my own work is a move away from psycho-social approaches that focus on internalised oppression, with a focus on intelligibility practices as co-constructed. As discussed in the previous chapter, it also makes a contribution to debates within psycho-social and QLR about analysis and representation.

### **Avenues for future outputs and further research**

The women's accounts presented in this thesis record experiences of neglect and misunderstandings in relation to maternity care, antenatal and postnatal education, the provision of personal assistance, and relationships with professionals. Following the collection of my data, significant failings of councils in meeting the needs of disabled parents have been reported (CSCI, 2009). In particular, it had become apparent that there was a failure of adult and child services to coordinate information in relation to family's needs (CSCI, 2009). A national survey into the experiences of disabled parents revealed that two-thirds of disabled parents were dissatisfied with the support from social and health care professionals and it was found that many healthcare professionals wanted further training and information about the needs of disabled parents (Disability Parenting Pregnancy International, 2009). My research could be used as a resource for

describing and addressing the needs of disabled parents in the teaching and training of health and social care professionals. In particular, recognition of the complex emotional dynamics involved in encounters with new parents and an understanding of intelligibility practices could lead to greater empathy and sensitivity to their support needs. This is crucial in relation to the evidence within my research of the emotional toll of intelligibility processes particularly in the context of limited support and recognition. Increasingly, British disability studies have been shifting towards an examination of Nordic models of disability that emphasise positive relationships with welfare providers (Goodley, 2011; Shakespeare, 2006). Qualitative longitudinal research that looks at encounters with health and social care professionals can help develop an understanding of dynamic processes of intelligibility particularly if using ethnographic observation (Thomson, 2010b). By allowing professionals to reflect on the emotional dynamics of their relationships with disabled clients it is possible to further enrich our understandings of co-constructions of disability.

In my analysis and writing, I have questioned whether - in my pursuit to mark out my research design as different from the MoMM project - I have neglected to fully explore and present the cultural resources women have drawn upon in their 'body projects' as drawn from the context of the common culture of motherhood. The absence of baby equipment that is adapted to suit the needs of disabled parents was a key theme in the research suggesting the importance of exploring further the ways in which consumption makes a significant impact on women's experience of inclusion and exclusion.

Moreover, when combined with insights from market research and occupational therapy, this examination could make real inroads into addressing the needs of disabled parents on an everyday basis.

In addition, I have managed only to skim the surface of the wealth of data that women presented in relation to the websites used to access information on equipment, specific impairment and illness needs in pregnancy, birth and early motherhood, and for general support and friendship (particularly in relation to interactions with health and social care professionals and access to formal support). Further exploration of these data could contribute to an increasing recognition of the potential of these sites as un-surveilled spaces in which women can contest and resist expert knowledge and, through the relative invisibility afforded by anonymity, provide women with 'transient breaks' from the tension between ideal and lived experiences of mothering (Mungham and Lazard, 2011, p 8; Madge and O'Connor, 2006). The implications here are significant, as others have argued the web is potentially a key site in which idealised traditional identities can be disrupted and deconstructed (Hardey, 2002). Further research with an explicit focus on researching disabled mothers in these online communities could reach a wider and more diverse sample. In the process, it would be valuable to contrast the way in which disabled women create these performances on both disabled parents forums and more mainstream sites like Mumsnet, reiterating some of the challenges women articulated in this study about common experiences and the significance of difference.

Women's body projects and intelligibility practices related to inter-generational patterns of promoting autonomy and social integration. This thesis only begins an analysis of these processes. One aspect of the data that I have not had space to explore is women's relationships with their husbands and the impact of the transition to motherhood on their relationships. By creating relational case studies (which would include interviews with significant others), it would be possible to map the way in which experiences of disability are made intelligible as a family project. This presentation would speak back to a wider project within disability studies to present disability in a relational context that takes into account the way disablism also affects others within the family (Goodley,

2011; Shakespeare, 2006). In addition, since the study, Magda, Amy and Kirsty have all had second babies. Inevitably, managing the physical and emotional challenges of a newborn with a toddler or young infant will pose new challenges for women. To further enrich our understanding of disabled motherhood, future empirical work would draw out the challenges across a longer temporal period that would include subsequent children, schooling, and young adulthood.

While previous work by Olsen and Clarke (2003) has identified the challenges parents face with children of different ages, there is not yet a study that has committed to following disabled parents over a long period. This would be an incredibly valuable area of study and particularly relevant for policy and practice, as it would reveal new challenges and the way in which women make them intelligible.

Throughout the study the question I have grappled with whether my focus was on the experience and understanding of the deconstruction of disability, or of motherhood. As my study reaches its conclusion, I find myself questioning what if? What if I had decided to examine the deconstruction of the significance of cultural constructions of motherhood as opposed to disability? Are women also questioning or making strange dominant social norms related to ideals and embodied practices of good mothering? The answer, of course, is that the distinction between the two is an illusion. As I have presented, women's 'body projects' and processes by which they make them intelligible both conform to and challenge ideas of good mothering and the idea of reproduction or mothering practices as natural and autonomous embodied experiences. It is here that I am reminded of Malacrida's (2009) argument that disabled motherhood is not fundamentally different yet magnifies issues that all women face. While I have attempted to address what is particular and what is common about disabled women's experiences of the transition to motherhood by drawing comparisons with findings from the MoMM project, this presentation could be extended and enriched. Further research

could draw out comparisons between the two data sets in more details in relation to the experience of conception, birth, expert advice, breastfeeding and consumption.

This balance between the common and particular embodied, emotional and subjective experience is paramount to our understanding and the potential deconstruction of normative constructions of difference. As I have argued, the realisation that embodied difference did matter in the transition to motherhood was both painful and liberating for the women in my study. During this significant period of questioning their difference, women found themselves in new social circumstances, meeting other mothers through community groups, and seeking out connections through online forums. It is this combination that has implications for political participation, the raising of awareness and, as I have presented, the potential for shared processes of intelligibility. Motherhood may well be the key to uniting women across lines of difference. On this note, I turn to my own processes of meaning making as I journeyed into motherhood towards the end of this study.

### **Reflecting back on women's journeys in a different temporal moment**

In this thesis I have tried to avoid the prioritisation of my own subjectivity over my participants, recognising that introspection is a core danger with psycho-social methods. Indeed, I have been reluctant to write this section for some time, fearful that my reflections on my own experience would appear trite in comparison with the challenges faced by the women in my study. Yet, as I moved from my painful experience of infertility towards my own transition into becoming a mother, women's accounts and the shared projects of intelligibility created within the interview dynamic were always present. As I faced the embodied challenges of birth, breastfeeding, fatigue, alongside a heightened visibility in birth, visits from health visitors and midwives, and greater participation in public settings, women's accounts echoed in my head. As I argued in the previous chapter, during moments in which my embodied experience were



challenged to new limits, I was afforded some insight into a fraction of the embodied limitations these women faced.

At times women's words were a great source of comfort and strength, related to women's messages:

'Everybody needs support, very hard to do it on your own anyway.' (Cathy, 1<sup>st</sup> interview)

At other times, particularly following encounters with midwives, health visitors, GPs, or the accident and emergency department in the children's hospital, I found myself in the unfamiliar territory of having to present myself as a competent mother. It was at these times that the real threat of misrecognition in women's experiences came to the fore, as Magda's words about her NCT friends who were struggling emotionally repeated in my memory;

'Yes but they are not disabled.' (Magda, 3<sup>rd</sup> interview)

Crucially, however, following a period of imagining my life without children, my journey into motherhood has been one of delight, enjoyment and amazement. Reflecting on these emotions, I realised the magnitude of the journey into motherhood for a group of women who are faced at every turn with the message that they are not expected to have children. This sheds a different light on the parallel body projects of their children, and any denial of negative emotions or of 'not coping'. For these women, the experience of having a child brings home the issue of reproduction as a basic human right, which forms the basis of disability politics.

It would be nice if I finished this thesis on that note. But since the collection of my data, the political climate has changed significantly in the UK in relation to disabled people's lives. The abolition of the current Disability Living Allowance in 2013 will see more

stringent testing of disabled people, including the introduction of health professionals to assess entitlement. Such tests have come under great criticism for their accuracy and further 'anxiety' about support cuts (Ramesh, 2012). The renewed authority of the medical professional in this process and criticisms related to the neglect of the temporal nature of impairment have implications for women's experiences in the transition to motherhood, particularly in relation to their interactions with health and social care professionals in assessment for support and accessing information. Yet there are other implicit effects, particularly in relation to media coverage of the proposed reforms. A recent study by Scope has highlighted how disabled people feel that media coverage has negatively affected attitudes towards them (Wood, 2012).

In the same year in which the statue of Alison Lapper Pregnant became a focal point for the opening ceremony of the Paralympics, David Cameron stated, in relation to proposed benefit reforms: 'We will help the strivers not the welfare claimants' (Hennessy, 2012). This emphasis on 'strivers' resonates with the theme of autonomy and determination that were so central to women's accounts. Indeed, as I have presented, it is the right to autonomy and self-determination that forms the core of disability politics in the UK, related in particular to disabled people's rights to direct payments and independent living (Morris, 2011). Historically, the UK disability movement has engaged with the dominant policy agendas of New Labour (in relation to choice and control) and Conservative government (in relation to autonomy and self-determination). The danger is, as Morris (2011) argues:

'... in engaging with the dominant policy agendas - we have lost touch with more fundamental issues concerning the welfare state, and that we have, unintentionally, contributed towards a steady undermining of collective responsibility and redistribution.' (p 3)

In this context, the transition to motherhood in which interdependency cannot be avoided may present a particularly difficult moment for disabled women as they attempt to manage their need for support with the presentation of themselves as competent mothers. Therefore, more than ever, there is a need for disability politics to engage with the experience of the transition to motherhood.

## **Appendix 1**

### **Original research questions**

- What discourses of mothers, pregnancy and disability are present in disabled British mothers' lives?
- How have discursive practices, positioning and investments shaped women's subjectivities, their experience and expectations of being/becoming a 'mother' (based on their own biography)? How is this cross cut with class and race?
- How do wider processes of anxiety work through discursive practices and what implications does this have for women's subjectivity and practices?
- How useful is the concept 'the other' for understanding disabled women's subjectivity and experience of interactions with non-disabled people?
- What can women's accounts tell us about the embodied experience of being disabled and 'expecting' in relation to their subjectivity?
- How can researcher subjectivity be used as part of the research and knowledge generated? Can the researcher position as 'non-mother' and 'non-disabled' actually benefit a deeper understanding of subjectivity, if attention is paid to unconscious processes between researcher and researched?
- If we lose the social model, do we lose the political objective of disability research?

## Appendix 2

### Interview schedule

| <b>Wave 1:</b>  | <b>Wave 2:</b>   | <b>Wave 3:</b>  |
|---|--|---|
| <b>Interview Schedule</b>   | <b>Interview Schedule</b>  | <b>Interview Schedule</b>   |
| Can you tell me about your life from birth to now?  | Can you tell me about life since the last time I saw you?  | Can you tell me about life since the last time I saw you?   |
| Can you tell me about your body/how you have/are experiencing your body in pregnancy? (include other sensory impairments where appropriate) | Can you tell me about the birth? Can you tell me about how you have experienced your body since? (include other sensory impairments where appropriate) | Can you tell me how you feel/have felt about your body? (include other sensory impairments where appropriate) |
| Can you tell me about what everyday life is like at the moment?   | Can you tell me about what everyday life is like at the moment?  | Can you tell me about what everyday life is like at the moment?   |
| Circle Map: Can you tell me about these relationships/networks/groups ?   | Circle Map: Can you tell me about these relationships/networks/groups ?  | Circle Map: Can you tell me about these relationships/networks/groups?  |
| Reflection and Looking Forward: Is there anything else you would like to tell me  | Reflection and Looking Forward: Is there anything else you would like to tell me   | Reflection and Looking Forward: Is there anything else you would like to tell me or                           |

|   |   |  |
|---|---|--|
| or that you feel we have missed?<br><br>Any thoughts and feelings about the future. Any reflections on interview/project participation. | or that you feel we have missed?<br><br>Any thoughts and feelings about the future. Any reflections on interview/project participation. | that you feel we have missed?<br><br>Any thoughts and feelings about the future. Any reflections on interview/project participation. |
|   |   | Reflection on Case<br><br>Themes/Opportunity to speak back to interpretations.   |

### **Rationale for use**

Each question was created in order to reflect the key aims of my research and my core research questions. I wanted to uncover the construction of disability in women's accounts of their lives and experiences in pregnancy and motherhood and women's emotional experiences, drawing on women's accounts of their experience of their bodies, to capture some of everyday thought and activity or practices and women's accounts of their relationships and interactions with others (family and peers, groups and professionals, and how these changed over time). To encourage the flow of the narrative and the participants' own narrative agenda, I encouraged participants to tell stories where possible by asking them to 'tell me more' or 'tell me about that'.

Interview questions were replicated in subsequent interviews and I also made notes of

key themes or phrases to follow up or attend to that were present in previous interviews. I abandoned the original FANI method of following up themes in close succession to the first interview instead incorporating themes into future interviews and, where pertinent, asking women to reflect back on changes or inconsistencies in their accounts. Rather than formulating them as interview questions, I would weave themes into the interview encouraging women to talk about them further if they were repeated. If a pertinent theme was not raised in the interview, I would try and bring it in towards the close of the interview.

### Appendix 3: The circle map

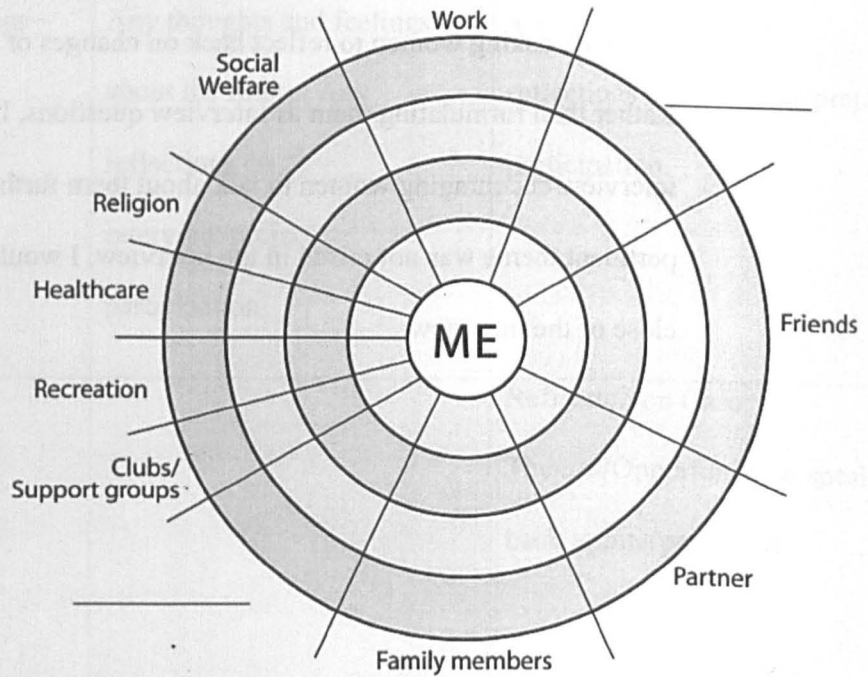
#### MY MAP OF SIGNIFICANT PEOPLE

Participant: \_\_\_\_\_

Date: \_\_\_\_\_

This circle map has been designed to help you think about all the people who have helped you or influenced you in becoming a mother. This may be people in the past who have given you ideas or support or people in the present. You may also want to talk about people who have been less supportive.

The map is in a series of circles with the circle in the middle representing you. Please demonstrate by writing or using the stickers provided the closeness of the people you feel are significant. I.e. if they are close to you on the map they are important, further away less important –even off the map! The circle map is divided into sections to demonstrate different groups of people. There are gaps for you to fill in if I have left any out.



In a circle map tool, the interviewee is placed at the centre of a series of concentric circles. The map is divided into a number of segments: family, partner, friends, support groups and clubs, recreation, work, health care, social care, religion, blank and blank. The closer people are placed to the participant on the map the more important or influential they are considered to be (Edwards *et al*, 2006). The map also enabled a more free narrative about particular interactions or encounters on a micro scale with professionals and within support groups. The circle map was also useful as a visual representation of change over time and, women were shown their maps from previous interviews to reflect on where necessary.

As Appendix 2 shows, interview questions were replicated in subsequent interviews. I also made notes of key themes or phrases to follow up or attend to that were present in previous interviews As discussed earlier in this section I abandoned the original FANI method of following up themes in close succession to the first interview, incorporating



themes into future interviews and where pertinent asking women to reflect back on changes or inconsistencies in their accounts. Rather than formulating them as interview questions I would weave themes into the interview encouraging women to talk about them further if they were repeated. If a pertinent theme was not raised in the interview I would try and bring it in towards the close of the interview

## Appendix 4

### Field-note framework

| Field-note Heading  | Description of Content   |
|---|--|
| Key Information   | Wave and Date of Interview<br><br>Date of Birth/Age<br><br>Definition of 'Disabled'<br><br>Due Date<br><br>Back to Work Date<br><br>Occupation<br><br>Marital Status/Living Arrangements |
| Themes/Phrases/Points to Follow (to be woven into interview schedule) | Taken from screening questionnaire, email/telephone exchange or from previous interviews.  |
| Negotiation of Interview Encounter                                    | Account of access: telephone exchange, email exchange.   |
| Reflection on the FANI Method.  | A record of the challenges of the method, where I felt it was working and any 'tangles of my own making'.  |
| Description of Research   | Including journey to interview, environment and  |

|   |   |
|---|---|
| Setting                                       | home, people present, interaction with others including baby.   |
| Description of Interviewee                    | Appearance/manner, also include description of baby.  |
| Description of Emotional Dynamic in Interview | Attention to interviewer feelings before, during and after the interview. Any notable gaps or silences/difficult moments in interview. Anything that interviewer feels maybe akin to transference/counter-transference. |
| Reflection on Research Questions              | Initial thoughts in relation to key research questions.   |
| Hopes and Fears for Participant               | Feelings directly after the interview and beyond - any concerns or hopes. Any predictions/anticipation of future events.  |

## Appendix 5

### Information sheet



**The Open University**

#### **Faculty of Health and Social Care**

The Open University

Horlock Building

Walton Hall

Milton Keynes

United Kingdom

MK7 6AA

T +44 (0)1908 655106

F +44 (0)1908 858280

W [www.open.ac.uk](http://www.open.ac.uk)

Participant ID Number:

## **Disabled Mothers: Expectations, Experiences and Identities**

### **An Information Sheet for Participants**

Thank you for taking an interest in my research project. I have made this information sheet to give you further information about my PhD study and myself. You will also be given an opportunity to ask questions before you take part.

#### **About Me**

My name is Lucy Hadfield. I am a part time PhD research student at the Open University and also a part time research fellow employed on a project called The Making of Modern Motherhoods which is funded by The Economic and Social Research Council. I am interested in families and identity and particularly the identity of disabled people.

#### **What is the Purpose of the Study?**

I would like to talk to 6 disabled women who expecting their first child about their experiences of expecting and of motherhood. I am interested in women's identity or your sense of who you are in relation to experiences of expecting and early motherhood. I am especially interested in how you feel about your body, your ideas about motherhood and the kind of support you have from friends, family, health professionals and support groups before and after the baby is born.

I want to produce a PhD study which will show a much more in depth or detailed picture of disabled mothers lives than has been shown in previous research. It will be a study that will look at the transitions (or moves) to becoming a mother at three different

stages: pregnancy, mother of child at 4 months and mother of child at 1 year.

### **\* 'Disabled' and 'Expecting'**

I am interested in what disability means to you. You may not consider yourself to be disabled but that might be how other people refer to you. Or you might consider yourself disabled but may not be registered disabled or have a medical impairment. If you have one your impairment might be important to you or it may seem irrelevant. Any of these cases make you eligible to take part in the study.

I would like to interview you if you are expecting your first child. I have chosen to refer to 'expecting' or 'expectations' of motherhood as opposed to pregnancy as I wish to include women who are 'expecting' a child either via pregnancy, surrogacy or adoption.

### **My Approach?**

The study is an in-depth look at disabled women's experiences using what is called a 'psycho-social' approach to understanding people's lives. I am interested in looking not just at the words that are said in the interview, but also things that happen in the interview, our feelings and emotions. I will use these as a way of understanding how people experience becoming a mother.

I would like to invite people to give me feedback on my research findings and interpretations at the end of my study. You may not want to do this as it may be time-consuming and it is not compulsory.

### **What Does Taking Part Involve?**

Taking part will involve three interviews which would usually take part in your home or somewhere you feel comfortable.

In the first interview we would chat about your life, your experiences of expecting a baby, your ideas about motherhood, your feelings about your body and the people who are important in supporting you and influencing your ideas about becoming a mother.

The second interview will happen 4 months after the arrival of your baby. In this interview we will talk about things that we discussed in the previous interview, the birth, what everyday life is like with the baby and the people who are supporting you.

The third and final interview will take place one year after the baby is born. In this interview we will talk about things that we discussed in the previous two interviews, your experience of motherhood and the people who are supporting you and your thoughts about the future.

How long the interview takes depends on how long you want to talk for but as a guide it will probably last about one hour and a half.

Following the meetings you can opt whether you would like to meet again to discuss my research findings.

**What are the possible disadvantages and risks of taking part?**

I hope that the experience of taking part will be enjoyable and rewarding. Some women may find talking about becoming a mother an emotional experience. In the case of any distress I will stop the interview.

**What are the possible benefits of taking part?**

I hope that the interview will be an enjoyable and rewarding experience. The experience may serve as a useful and welcome record of the pregnancy and birth of your first child.

### **Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you agree to take part you are still free to withdraw at any time and without giving a reason.

### **Privacy and Confidentiality**

#### **What happens to the interviews?**

Interviews will be transcribed and stored securely in digital form at The Open University. This data will be held at the Open University for the five year duration of the PhD. Personal data on workstation fixed hard discs have adequate protection e.g. password access to files to prevent un-authorised access. Contact detail sheets will be removed and stored separately in locked cabinets. All respondents will be given a code number and pseudonym. Personal information such as name, corresponding code number, address of respondent will be kept in a separate data base. Back up of this personal information will also be held in paper copy in a locked filing cabinet. Identifying material in interviews will be marked up at the point of transcription.

#### **Will my taking part in this study be kept confidential?**

All information that is collected about you during the course of the research will be kept strictly confidential. I will ensure that individuals cannot be recognised in my final report (thesis) or publications. I will not use real names and I will change information that might identify people to others who know them.

#### **Is there a chance confidentiality might be broken?**

Everything you say in this interview will be kept confidential. By this, I mean that if I use your words, your name and other identifying details will be altered in reports, publications etc. and only I will know your real name. However I may have to disclose



your name and details if you tell me something that makes me worry about your safety or the safety of your baby. For example I may worry that either of you may be in danger of being harmed by somebody or that your baby may be at risk of abuse or neglect. In this case I would like to talk to somebody about getting you help. I would only do this after talking to you first about my concerns and letting you know what will happen next.

**What will happen to the results of the research study?**

All those who take part in interviews will be offered copies of the interview transcripts and a summary of research findings. The research findings are likely to be published in academic journal articles.

**Who has reviewed the study?**

The Open University Ethics Committee has reviewed this study.

**Contact for Further Information**

Lucy Hadfield: [l.s.hadfield@open.ac.uk](mailto:l.s.hadfield@open.ac.uk) 01908 855106

**Thank you for taking part in this study**

Version no: 3 (11/02/07)

Each interviewee will be given a copy of the information sheet and a signed consent form to keep.

## Appendix 6

### Consent form



**The Open University**

#### **Faculty of Health and Social Care**

The Open University

Horlock Building

Walton Hall

Milton Keynes

United Kingdom

MK7 6AA

T +44 (0)1908 655106

F +44 (0)1908 858280

W [www.open.ac.uk](http://www.open.ac.uk)

Participant ID Number:

## **CONSENT FORM**

**Title of project: Becoming a Disabled Mother:**

**Names of researcher: Lucy Hadfield**

### **Part 1. Before we start the interview:**

**Please initial box**

1. I confirm that I have read and understand the information sheet  
dated 11/02/07..... (version .3.) for the above study and have had the  
opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any  
time, without giving any reason, without my  
medical care or legal rights being affected.
3. I understand that everything I say in the research interview is confidential and the  
researcher will ensure that there is no way that I can be identified.
4. I understand that if I tell the interviewer something that makes her worry about my  
safety or the safety of my baby, that either of us may be in danger of being harmed,  
or that my baby is at risk of abuse or neglect, she would like to talk to somebody  
about getting me help. I accept the researcher would only do this after talking to me  
first about their concerns and what she would like to do next. I accept that in cases  
such as above the researcher will break confidentiality by disclosing identities and  
information to the relevant services

5. I agree to take part in the above study.

**Part 2. After the interview:**

6. I agree that my anonymised research interview will be securely stored within the Open University for the duration of the project

7. I understand my contribution will be kept safely and securely with access only to those with permission from Lucy Hadfield. I understand that I can withdraw my consent at any time by contacting Lucy Hadfield. I assign copyright in my contribution to Lucy Hadfield.

8. I give Lucy Hadfield permission to quote any of my words used in my interview for publications and reports.

9. I give my permission for the information I have given to be used for research purposes only (including research publications and reports)

- with strict preservation of anonymity
- without preservation of anonymity

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Name of Participant

Date

Signature

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

*Thank you for taking part in this study*

*Each interviewee will be given a copy of the information sheet and a signed consent form to keep.*

**Contact for Further Information**

Lucy Hadfield: 01908 655106 [l.s.hadfield@open.ac.uk](mailto:l.s.hadfield@open.ac.uk)

for participant; for researcher

Version No: 3

Date: 11/02/07

## **Appendix 7**

### **Account of ethical considerations**

Before access and fieldwork could commence, I had to gain ethical approval for the proposed research from The Open University Human Research Ethics Committee. The committee was sent information on my aims and research questions, theoretical and methodological outline, justification of the research, my consideration of BSA ethical guidelines, plans for access (including location, time and sample composition), consideration of ethics (including copies of my consent form), information sheet, considerations of risk for my participants and acts to safeguard against this, and information on the storage and disposal of data to comply with the data protection act. Initially, I had included information on the gift voucher intended as a thank you gesture for taking part, but this was removed under the guidance of the committee, because it was considered an inducement for participation. The project was given ethics approval on 22<sup>nd</sup> September 2006 (Ref HPMEC/06/#255/1).

All of my participants were given an information sheet that contained information about myself and the project (see Appendix 1). I wanted to make the psycho-social nature of my research apparent, but doing so in accessible language was difficult. Under the guidance of the Open University Human Research Ethics Committee, I redesigned my information sheet to describe as well as possible in lay terms how my research differed from standard interviews:

‘I am interested in looking not just at the words that are said in the interview, but also things that happen in the interview, our feelings and emotions. I will use these as a way of understanding how people experience becoming a mother.’

While this statement could be seen as a somewhat 'vague' description of the method, participants were also given the opportunity to discuss the method further during and after the interview and I was quite open about the process of recording thoughts and feelings following the interviews. While one participant (Amanda) showed initial signs of anxiety about my interest in emotions, other participants actively engaged in the idea of assessing emotions, emailing me after the interview to discuss how they felt after I left. In addition, all participants were given opportunities to reflect on the interview, including their own emotions at the end of each interview. Opportunities for reflecting on my own interpretation of the emotional dynamic and observations were made at the end of the last case interview, allowing participants to speak back to my interpretations.

My information sheet also provided information on the content of each of the three interviews, the areas we would discuss, and an approximate length of interview duration, information on privacy and confidentiality (including data storage and anonymisation), and when confidentiality may be broken (for safety reasons). From the outset, I recognised that informed consent would not be a one-off event and outlined a three-step procedure within my ethics application. Firstly, information sheets and consent forms were given to participants in advance to allow time to digest information on the project and consider participation; further information and opportunities for questions on the study would be given before interviewing. The consent form itself would work in stages, the first being consent for participants to be interviewed and the second, after the interview, to agree ownership of the data and use of quotes in the thesis and publication (see Appendix 6). These steps (building on an approach devised for the MoMM project) reflected the fact that I recognised that participants may not necessarily know what they are consenting to (what they will say or what emotions may emerge) until the interview has ended. The information sheets highlight that participation was voluntary and they were given the additional option of contacting my

supervisor, Sheila Peace, if she wished to discuss the project further. Longitudinal studies are particularly vulnerable to sample attrition. To safeguard against this, I made the distinction between complete withdrawal (in which case all data would be destroyed) and partial withdrawal in cases where participants do not wish to withdraw their contribution but are not able to participate in the full three interviews. In the course of the research, however, my only participant to pull out of the research process was my pilot interviewee Vanessa.

In relation to safeguarding my participants, I was relatively well prepared at the stage of ethical approval, drawing on both the experiences of the MoMM project and the BAM project. In particular, I recognised the sensitive nature of the subject matter and particular vulnerabilities of participants in pregnancy and the transition to motherhood. Drawing on the experience of these two projects, I put together an information pack of contact details of national support organisations and helplines. I also considered how I would manage unforeseen upset within the interview and how I would handle the potential need to break confidentiality where I was concerned about the safety of a mother and/or her child (consulting social services with my supervisors being the first source of support/advice). While I had detailed these procedures in my information sheet, I also stated that I would discuss my concerns with the participants during the interview, based on the premise that any suspected secrecy would cause participants unnecessary anxiety. This preparation shows some sense of foresight about potential fears about professional intervention. Despite these safeguards, however, I had not fully considered the impact of participant and researcher defences against being perceived/constructed as not 'coping' and the implications for access to support as I discuss in Chapter 3.



## Bibliography

Adkins, L. (2002) 'Reflexivity and the Politics of Qualitative Research', in T. May (ed) *Qualitative Research in Action*, London, Sage Publications.

Bailey, R. (1996) 'Prenatal testing and the prevention of impairment: a woman's right to choose?', in J. Morris (ed) *Encounters with strangers: Feminism and Disability*, London, Women's Press.

Baraitser, L. (2008a) *Maternal Encounters: The Ethic of Interruption*, London, Routledge.

Baraitser, L. (2008b) 'On giving and taking offence', *Psychoanalysis, Culture and Society*, vol. 13, no. 4 pp 423-427.

Barnes, C. (1997) 'Disability and the myth of the independent researcher', in L. Barton & M. Oliver (eds), *Disability studies: Past present and future*. Leeds, The Disability Press.

Barnes, C. (2012) 'The Social Model of Disability: Valuable or Irrelevant?', in N. Watson, A. Roulstone and C. Thomas, 2012: *The Routledge Handbook of Disability Studies*, London, Routledge, pp 12-29.

Barnes C. and Mercer, G. (2010) *Exploring Disability: 2nd Edition*, Cambridge, Palgrave.

Begum, N. (1992) 'Disabled Women and the Feminist Agenda', *Feminist Review*, vol. 40, pp 70-84.

Benhabib, S. (1986) *Critique, Norm and Utopia: A Study of the Foundations of Critical Theory*, New York, Columbia University Press.

- Betterton, R. (2002). 'Prima gravida. Reconfiguring the maternal body in visual representation', *Feminist Theory*, vol. 3, no.3, pp 255-270.
- Betterton, R. (2009) 'Promising Monsters: Pregnant Bodies, Artistic Subjectivity and Maternal Imagination' in N. Sullivan and S. Murray, *Somatechnics: Queering the technologization of bodies* (Queer interventions), Farnham: Ashgate.
- Bigwood, C. (1998) 'Renaturalising the Body (with the help of Merleau-Ponty)', in D. Welton (ed), *Body and Flesh: A Philosophical Reader*, (ed) Oxford, Blackwell, pp 99-114.
- Bjerrum Nielsen, H. (1996) 'The magical writing pad - on gender and identity', *Young: Journal of Nordic Youth Studies*, vol. 4, no. 3, pp 2-18.
- Booth, T. and Booth, W. (1994) *Parenting under pressure: Mothers and fathers with learning difficulties*, Buckingham, Open University Press.
- Bordo, S. (1993) *Unbearable Weight: Feminism, Western Culture, and the Body*, Berkeley, University of California Press.
- Butler, J. (1990) *Gender Trouble*, New York, Routledge.
- Butler, J. (1993) *Bodies That Matter: On the Discursive Limits of 'Sex'*, New York, Routledge.
- Butler, J. (2004) *Undoing Gender*, New York, Routledge.
- Butler, J. (2005) *Giving An Account of Oneself*, New York, Fordham University Press.
- Byrne, B. (2006) *White Lives: the interplay of 'race', class and gender in everyday life*, London, Routledge.
- Campbell, J. and Oliver, M. (1996) *Disability Politics: Understanding Our Past, Changing Our Future*, London, Routledge.

Campion, M. J. (1995). *Who's Fit to be a Parent?* London, Routledge.

Clarke, H. (2009) 'Experiencing Disability', in C. Squire (ed), *The Social Context of Birth*. Oxford, Radcliffe.

Clarke, S. and Hoggett, P. (2009) *Researching Beneath the Surface*, London, Karnac Books.

Clarke, H and Lewis, A (2008) 'Disability', in Morris, K., Hughes, N., Clarke, H., Tew, J., Mason, P., Galvani, S., Lewis, A., Loveless, L., Becker, S., Burford, G. (eds), *Think family: A literature review of whole family approaches*, Cabinet Office, Social Exclusion Task Force.

Commission for Social Care Inspection (CSCI) (2009) *Supporting disabled parents. A family or a fragmented approach?* February 2009. (Online). Available at: <http://dera.ioe.ac.uk/8785/1/Disparents.pdf> (Accessed 2/02/2013).

Cooke, R. (2005) 'Bold, brave, beautiful', *The Observer*, September 18, 2005, p 10.

Corker, M. and French, S. (1999) 'Reclaiming Discourse in Disability Studies', in M. Corker and S. French (eds), *Disability Discourse*. Buckingham, Open University Press.

Crawford, J., Kippax, S., Onyx, J., Gault, U., and Benton, P. (1992) *Emotions and Gender: Constructing Meaning from Memory*, London, Sage..

Cross, M. (1999) *Proud Child. Safer Child: A Handbook for Parents and Carers of Disabled Children*, London, The Women's Press.

Crow, L. (1996) 'Including All Our Lives: Renewing the Social Model of Disability', in C. Barnes and G. Mercer (eds), *Exploring the Divide: Illness and Disability*, Leeds, The Disability Press.

Crow, L. (2003) *Invisible and centre stage: a disabled woman's perspective on maternity services*, paper presented at Department of Health Open Forum Event of the Children's National Service Framework (Maternity Module) in January 2003. (Online) Available at:

<http://www.leeds.ac.uk/disabilitystudies/archiveuk/Crow/Invisible%20and%20centre%20stage.0302.pdf> (Accessed 21/5/2010).

Davis, F. (1961) 'Deviance Disavowal: The Management of Strained Interaction by the Visibly Handicapped', *Social Problems*, vol. 9, pp 120-32.

Davis, K. (2008) 'Intersectionality as buzzword: A sociology of science perspective on what makes a feminist theory successful', *Feminist Theory*, vol. 9, pp 67-85.

Davis, L.J. (1997) 'Nude Venuses, Medusa's Body, and Phantom Limbs: Disability and Visuality', in: D.T. Mitchell, D.T. and S.L. Snyder (eds), *The Body and Physical Difference: Discourses of Disability*. Michigan, The University of Michigan Press.

de Beauvoir, S. (1949) *The Second Sex*, (trans. H.M Parshley 1983), Harmondsworth, Penguin.

Disabled Parents and Professionals International, (2009) *The maternity information gap for disabled people*. (Online). Available at:

<http://www.dppi.org.uk/projects/episurvey.php>. (Accessed 2/02/2013).

Dyson, L., Renfrew, M., McFadden, McCormick, A.F., Herbert, G. and Thomas, J (2006). *Promotion of breastfeeding initiation and duration. Evidence into Practice Briefing*, Public Health Collaborating Centre on Maternal and Child Nutrition, July 2005. (Online). Available at:

[http://www.nice.org.uk/aboutnice/whoweare/aboutthehda/hdapublications/promotion\\_of](http://www.nice.org.uk/aboutnice/whoweare/aboutthehda/hdapublications/promotion_of)

[breastfeeding\\_initiation\\_and\\_duration\\_evidence\\_into\\_practice\\_briefing.jsp](#) (accessed 2/02/2013).

Edwards, R., Hadfield, L., Lucey, H. & Mauthner, M. (2006) *Sibling Identity and Relationships: Sisters and Brothers*. London, Routledge.

Elliott, H. (2011) 'Interviewing mothers: reflections on closeness and reflexivity in research encounters', *Studies in the Maternal*, 3 (1). (Online) Available at: [www.masmie.bbk.ac.uk/Elliott\\_SiM3](http://www.masmie.bbk.ac.uk/Elliott_SiM3) (1) 2011.pdf. (Accessed 2/04/2013).

Elliott, H, Gunaratnam, Y., Hollway, W. and Phoenix, A. (2009) 'Meaning, practices and identity change in the transition to becoming a mother' in M. Wetherall (ed), *Theorizing Identities and Social Action*. Basingstoke, Palgrave Macmillan.

Elliott, H., Ryan, J., and Hollway, W. (2011) 'Research encounters, reflexivity and supervision', *International Journal of Social Research Methodology*, vol.15, no. 5, pp 433-444.

Evans, J. (1992) 'Infantilism, Projection and Naturalism in the Construction of Mental Disablement', in D. Hevey, *The Creatures Time Forgot*, London, Routledge.

Fawcett, B. (2000) *Feminist Perspectives on Disability*. London, Prentice Hall.

Featherstone, M. (1991) *Consumer Culture and Postmodernism*, London, Sage.

Featherstone, M. (ed) (2000) *Body Modification*, London, Sage.

Finch, J. (1987) 'Whose responsibility? Women and the future of community care' in I Allen, M. Wicks, J. Finch and D. Leat (eds), *Informal Care Tomorrow*, London, Policy Studies Institute.

Finger, A. (1990) *Past Due: A Story of Disability, Pregnancy and Birth*, Seattle, Seal Press.

- Foucault, M. (1973) *The Birth of the Clinic. An Archaeology of Medical Perception*, London, Tavistock Publications.
- Foucault, M. (1979) *The History of Sexuality. Volume 1. An Introduction*. London, Penguin Books.
- Foucault, M. (1981) 'The Order of Discourse', (trans R. Young), in *Untying the Text: A Poststructuralist Reader*, R. Young (ed) London, Routledge.
- Franklin, S. (1991) 'Fetal Fascinations: New Dimensions to the Medical - Scientific Construction of Fetal Personhood', in S. Franklin, C. Lury and J. Stacey (eds), *Off Centre: Feminism and Cultural Studies*. London, Harper Collins.
- Fraser, N. and Gordon, L. (1994) 'A genealogy of dependency: tracing a keyword of the US welfare state.' *Signs*, vol. 19, no. 2, pp 309-34.
- Frohmader, C. (2009) *Parenting Issues for Women with Disabilities in Australia. A Policy Paper by Women with Disabilities Australia (WWDA)*, May 2009. (Online) Available at: <http://www.wwda.org.au/parentingpolicypaper09.pdf> (Accessed 13/08/2013).
- Frosh, S. and Baraitser, L. (2008) 'Psychoanalysis and psychosocial studies', *Psychoanalysis, Culture and Society*, vol. 13, pp 346-365.
- Garland-Thomson, R. G. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York, Columbia University Press.
- Garland-Thomson, R. G. (2002) 'The politics of staring', in S L Snyder, B J Brueggemann, R G Thomson (eds) *Disability Studies*, Modern Language Association, New York, pp 56-75.

- Gibson, B. (2006) 'Disability, Connectivity and Transgressing the Autonomous Body', *Journal of Medical Humanity*, vol. 27, pp 187-197.
- Giddens, A. (1991) *Modernity and Self-Identity. Self and Society in the Late Modern Age*, Cambridge, Cambridge Polity Press.
- Gilleard, C. and Higgs, P. (2013) *Ageing, Corporeality and Embodiment*, London, Anthem Press.
- Gilligan, C. (1982) *In a Different Voice: psychological theory and women's development*. Cambridge, Mass, Harvard University Press.
- Gilson, S.F, Tusler, A., and Gill, C. (1997) 'Ethnographic research in disability identity, self-determination and community', *Journal of Vocational Rehabilitation*, vol. 9, pp 7-17.
- Goffman, E. (1968) *Stigma. Notes on the Management of Spoiled Identity*, Harmondsworth, Penguin.
- Goodley, D. (2011) *Disability Studies: An Interdisciplinary Introduction*, London, Sage.
- Grosz, E. (1994). *Volatile Bodies: Toward a Corporeal Feminism*, Bloomington and Indianapolis, Indiana University Press.
- Hadfield, L. (2005) The Importance of the Visual Image for The Making of Modern Motherhoods, BSA Sociology of Reproduction Annual Conference, Milton Keynes, 8<sup>th</sup> December 2005.
- Hadfield, L. (2008a) "I could get away with it because she looks so much like me": Reflections on visible and invisible bodies and connections in the process of becoming a disabled mother through surrogacy' paper presented at Health and Social Care Postgraduate Research Seminar, The Open University, 31st March 2008.

Hadfield, L. (2008b) 'Natural or Normal? Surrogacy, Anxiety and Becoming a Disabled Mother', paper presented at British Sociological Association Annual Conference, Natural and Cultural Worlds, Warwick University. 29th March 2008.

Hadfield, L. (2008c) 'Becoming a Disabled Mother', paper presented at the ESRC Disabled Parents Gender Matters Seminar, University of Birmingham, 22<sup>nd</sup> September 2008.

Hadfield, L. (2009) 'Conviviality and maternity: anticipating childbirth and negotiating intergenerational difference', *Birth: Feminist Review Special Issue*, 93:1 (November 2009).

Hadfield, L. (2010a) 'Putting Disabled Maternal Bodies into Perspective', paper presented at the British Sociological Association Annual Conference (Inequalities and Social Justice), Glasgow-Caledonian University, 7-9<sup>th</sup> April 2010.

Hadfield, L. (2010b) Balancing on the Edge of the Archive: The Researcher's Role in Collecting and Preparing Data to Deposit in Conducting Qualitative Longitudinal Research, *Timescapes Working Paper 2*:

[http://www.timescapes.leeds.ac.uk/assets/files/WP2\\_final\\_Jan%202010.pdf](http://www.timescapes.leeds.ac.uk/assets/files/WP2_final_Jan%202010.pdf)

Hadfield, L., Thomson, R. (2009) 'Making birth plans: Findings from a qualitative research project', *Practising Midwife*, vol. 12 no.7 (July/August), pp 32-33.

Hall, S. & Gieben, B. (eds) (1992) *Formations of Modernity*. Cambridge, Polity Press/Milton Keynes, The Open University Press.

Haraway, D. (1991) *Simians, Cyborgs and Women: The Reinvention of Nature*. New York, Routledge.

Hardey, M. (2002) 'Life beyond the screen: embodiment and identity through the Internet', *Sociological Review*, vol. 50, pp 570-585.



Hasler, F. (1993) 'Developments in the Disabled People's Movement', in J. Swain, V. Finklestein, S. French and M. Oliver (eds), *Disabling Barriers - Enabling Environments*. London, Sage.

Henderson, S., Holland, J., McGrellis, S., Sharpe, S and Thomson, R. (2007) *Inventing Adulthood: A Biographical Approach to Youth Transitions*, London, Sage.

Hennessy, P. (2012) 'David Cameron: we'll help the strivers, not welfare claimants', *The Telegraph*, 30th December 2012. (Online). Available at <http://www.telegraph.co.uk/news/politics/david-cameron/9770922/David-Cameron-well-help-the-strivers-not-welfare-claimants.html> (Accessed 30/12/12).

Heslinga, K., Schellen, A. and Verkuyl, A. (1974) *Not made of stone: The sexual problems of handicap people*, Springfield, Charles C. Thomas Publishing.

Hevey, D. (1992) *The Creatures Time Forgot: photography and disability imagery*, London, Routledge.

Holland, J., Thomson, R. and Henderson, S. (2004), *Feasibility Study for a Possible Longitudinal Study: Discussion Paper*, [www.lsbu.ac.uk/inventingadulthoods/feasibility\\_study.pdf](http://www.lsbu.ac.uk/inventingadulthoods/feasibility_study.pdf).

Hollway, W. (1984) 'Gender Difference and the Production of Subjectivity', in J. Henriques., W. Hollway, C. Urwin, C. Venn and V. Walkerdine (eds), *Changing the Subject*, London, Methuen.

Hollway, W. (1989) *Subjectivity and Method in Psychology: Gender, Meaning and Science*. London, Sage.

Hollway, W. (2010) 'Preserving Vital Signs: the use of psychoanalytically informed interviewing and observation in psycho-social longitudinal research', in R. Thomson

(ed), *Intensity and Insight: Qualitative Longitudinal Methods as a Route to the Psycho-social*, Timescapes Working Paper Series, No.3.

Hollway, W. and Jefferson, T. (2000) *Doing Qualitative Research Differently: Free Association, Narrative and the Interview Method*, London, Sage.

Hollway, W. and Jefferson, T. (2013) *Doing Qualitative Research Differently: A Psycho-social Approach, 2<sup>nd</sup> Edition*. London, Sage.

Hollway, W., Phoenix, A., Elliott, H., Urwin, C., Gunaratnam, Y. (2008) *Identities in process: Becoming Bangladeshi, African Caribbean and White mothers*, ESRC Key Findings Paper.

Hughes, D. and Paterson, K. (1997) 'The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment', *Disability & Society*, vol.12, pp 325-40.

Jamison, R. and Walker, L. (1992) 'Illness behavior in children of chronic pain patients', *International Journal of Psychiatry in Medicine*, vol. 22, no. 4, pp 329-42.

Johnson, M. (2003) 'Surrogacy and the Human Fertilisation and Embryology Act', in R.Cook, S. Day Sclater, F. Kaganas (eds), *Surrogate Motherhood: International perspectives*, Oxford/Portland Oregon, Hart publishing.

Kirkman, M., Harrison, L., Hiller, L. and Pyett, P. (2001) "I know I am doing a good job": canonical and autobiographical narratives of teenage mothers', *Culture, Health and Sexuality*, vol. 3, no. 3, pp 279-94.

Klien, M. (1946) 'Notes on some schizoid mechanisms', *International Journal of Psycho-Analysis*, 27: pp 99-110; republished (1952) in M. Klien, P. Heimann, S. Isaacs and J. Riviere, *Developments in Psychoanalysis*. London, Hogarth Press.

- Laplanche, J. (1999) *Essays on Otherness*, Oxon/New York, Routledge.
- Lapper, A. (2006) *My Life in My Hands*, London, Pocket Books.
- Lawler, S. (2000) *Mothering the self: Mothers, daughters, subjects*, London: Routledge.
- LeClere, F. and Kowalewski, B. (1994) 'Disability in the family: the effects on children's wellbeing', *Journal of Marriage and the Family*, vol. 32, no. 5, pp 36-57.
- Lewis, J. (1992) *Women in Britain since 1945*, Oxford, Blackwell.
- Lingsom, S. (2008) 'Invisible Impairments: Dilemmas of Concealment and Disclosure', *Scandinavian Journal of Disability Research*, vol. 10, no. 1, pp 2-16.
- Lucey, H. (2004) 'Differentiated Citizenship: psychic defence, social division and the construction of local secondary school markets', in G. Lewis, (ed), *Citizenship: Personal Lives and Social Policy*. Bristol: Policy Press, pp 85-120.
- Longhurst, R. (2001) *Bodies: Exploring Fluid Boundaries*, Routledge, London.
- Longhurst, R. (2008) *Maternities: Gender, Bodies and Space*, New York, Routledge.
- Longsdale, S. (1990) *Women and disability*. New York: St Martins Press.
- Madge, C., & O'Connor, H. (2006) 'Parenting gone wired: Empowerment of new mothers on the internet?' *Social & Cultural Geography*, 7, pp 199-220.
- Magnet, A. (2012) 'Fandom, Shame and Identification in Morrissey's 'Disability Chic' Movement' paper presented at Cripples, Idiots, Lepers, and Freaks: Extraordinary Bodies/Extraordinary Minds Conference, CUNY Graduate Center; New York, 23/03/12. (Online) Available at <http://www.academicroom.com/conferencepaper/fandom-shame-and-identification-morrisseys-disability-chic-movement> (Accessed on 21/08/2013).

- Malacrida, C. (2007) 'Negotiating the Dependency/Nurturance Tightrope: Dilemmas of Motherhood and Disability', *Canadian Review of Sociology*, vol. 44, no.4, pp 469-493.
- Malacrida, C. (2009) 'Performing motherhood in a disabilist world: dilemmas of motherhood, femininity and disability', *International Journal of Qualitative Studies in Education*, vol. 22, no.1, pp 99-117.
- Mallet, R. (2007) *Critical correctness: exploring the capacities of contemporary Disability criticism*, unpublished PhD thesis, University of Sheffield.
- Marks, D. (1999) *Disability Controversial Debates and Psychosocial Perspectives*, London, Routledge.
- Mauthner, N.S. (1999) 'Feeling low and feeling really bad about feeling low': Women's experiences of motherhood and postpartum depression', *Canadian Psychology*, vol. 40, pp 1-30.
- McFarlane, H. (2004) *Disabled Women and Spatial Social 'Barriers' to Motherhood*, PhD unpublished PhD thesis, Faculty of Social Sciences, University of Glasgow.
- McKie, L., Gregory, S. and Bowlby, S. (2002) 'Shadow Times: The Temporal and Spatial Frameworks and Experiences of Caring and Working', *Sociology*, vol. 36, no. 4, pp 897-924.
- McLeod, J. (2003) 'Why we interview now - reflexivity and perspective in a longitudinal study', *International Journal of Social Research Methodology*, vol. 6, no.3, pp 201-12.
- McLeod, J. and Yates, L. (2006) *Making Modern Lives: Subjectivity Schooling and Social Change*. Albany, New York, State University of New York Press.

- McLeod, J. and Thomson, T. (2009) *Researching change: qualitative approaches to personal, social and historical processes*, London, Sage.
- Meekosha, H. (1998) 'Body Battles: Bodies, Gender and Disability', in T. Shakespeare (ed), *The Disability Reader: Social Science Perspectives*, London, Continuum, pp 163-80.
- Miller, T. (2005) *Making Sense of Motherhood: A Narrative Approach*, Cambridge, Cambridge University Press.
- Mitchell, J. (1974) *Psychoanalysis and Feminism*, New York, Pantheon Books.
- Morris, J. (1989) *Able Lives: Women's Experience of Paralysis*, London, The Women's Press.
- Morris, J. (1991) *Pride Against Prejudice: Transforming Attitudes to Disability*, London, The Women's Press.
- Morris, J. (1993) *Independent Lives? Community Care and Disabled People*, London, Macmillan.
- Morris, J. (ed) (1996) *Encounters with Strangers: Feminism and Disability*, London, The Women's Press.
- Morris, J. (1997) 'Care or Empowerment? A Disability Rights Perspective', *Social Policy and Administration*, vol. 31, no. 1, 54-60.
- Morris, J. (1998) 'Feminism, Gender and Disability', Text of a paper presented at a seminar in Sydney, Australia: February 1998. <http://www.leeds.ac.uk/disability-studies/archiveuk/morris/gender%20and%20disability.pdf>. (Accessed 02/07/2007).
- Morris, J. (2003) *The right support: Report of the Task Force on Supporting Disabled Adults in their Parenting Role*, London, The Jacob Rowntree Foundation.

- Morris, J. (2011) *Rethinking disability policy*, London, Jacob Rowntree Foundation.
- Morris, J. and Wates, M. (2006) *Supporting disabled parents and parents with additional support needs*, Bristol, The Policy Press.
- Mungham and Lazard, (2011) 'Virtually Experts: Exploring constructions of mothers' advice-seeking in online parenting communities', *Radical Psychology: A Journal of Psychology, Politics & Radicali*., Vol. 9 Issue 2, p 8
- Neale, B. and Flowerdew, J. (2003) 'Time, texture and childhood: the contours of longitudinal qualitative research', *International Journal of Social Research Methodology*, vol. 6, no. 3, pp 189-99.
- Oakley, A. (1980) *Women Confined: Towards a Sociology of Childbirth*. Oxford, Martin Robertson.
- Oliver, M. (1983) *Social Work with Disabled People*, Basingstoke, Macmillan.
- Oliver, M. (1990) *The Politics of Disablement*, London, Macmillan.
- Oliver, M. (1992) 'Changing the social relations of research production?' *Disability, Handicap and Society*, vol. 7, no.2, pp 101-114.
- Oliver, M. (1993) *Disability, Citizenship and Empowerment*, Milton Keynes, Open University Press.
- Oliver, M. (1996) *Understanding Disability from Theory to Practice*, Basingstoke, Macmillan.
- Oliver, M. (1997) 'Emancipatory Research: Realistic Goal or Impossible Dream?', in C. Barnes and G. Mercer (eds), *Doing Disability Research*. Leeds, The Disability Press, pp 15-31.

- Oliver, M. and Barnes, C. (1998) *Disabled People and Social Policy: From Exclusion to Inclusion*, London, Longman.
- Olkin, R. (2009) *Women with Physical Disabilities who Want to Leave their Partners: A Feminist and Disability Affirmative Perspective*, California School of Professional Psychology and Through the Looking Glass Co.
- Olsen, R. and Clarke, H. (2003) *Parenting and Disability: Disabled Parents' Experiences of Raising Children*, Bristol, The Policy Press.
- Olsen, R. and Wates, M. (2003) 'Disabled Parents: Examining Research Assumptions', *Research in Practice*. (Online) Available at [www.rip.org.uk](http://www.rip.org.uk) (Accessed 2/11/2006).
- Paul, A., Cawson, P., Paton, J. (2004) *Safeguarding Disabled Children in Residential Special Schools*, London, NSPCC.
- Pearce, L. (2004) *The Rhetorics of Feminism: Readings in Contemporary Cultural Theory and the Popular Press*, London, Routledge.
- Phoenix, A. (1994) 'Practising feminist research. The intersection of gender and 'race' in the research process', in M. Maynard & J. Purvis (1994) (eds) *Researching Women's Lives*. Basingstoke, Taylor & Francis, pp 72-93.
- Price, J. and Shildrick, M. (1998) Uncertain Thoughts on the Dis/abled Body, in J. Price and M. Shildrick, *Vital Signs: Feminist Reconfigurations of the Bio/logical Body*, Edinburgh, Edinburgh University Press, pp 244-249.
- Pritchard, M. (2005) 'Can there be such thing as a wrongful birth'?, *Disability and Society*, vol.20, no.1, pp 81-93.
- Priestley, M. (2003) *Disability: A Life Course Approach*, Cambridge, Polity.

- Priestley, M., Corker, M., and Watson, N. (1999) 'Unfinished business: disabled children and disabled identity', *Disability Studies Quarterly*, vol.19, no. 2, pp 87-98.
- Prilleltensky, O. (2003) 'A Ramp to Motherhood: The Experiences of Mothers with Physical Disabilities', *Society and Disability*, Vol. 21, No. 21, pp 21-47.
- Prilleltensky, O. (2004) *Motherhood and Disability: Children and Choices*. Basingstoke, Palgrave Macmillan.
- Ramazanoglu, C. and Holland, J. (2002) *Feminist Methodology: Challenges and Choices*. London, Sage.
- Ramesh, R. (2012) 'Atos wins £400m deal to carry out disability benefits tests', in *The Guardian*, 2<sup>nd</sup> August 2012. (Online). Available at: <http://www.theguardian.com/society/2012/aug/02/atos-disability-benefit-tests> (Accessed 30/12/2012).
- Reynolds, R. (2002) *From Camp to Queer: Remaking the Australian Homosexual*, Melbourne, Melbourne University Press.
- Reeve, D. (2006) 'Towards a psychology of disability: the emotional effects of living in a disabling society', in D. Goodley and R. Lawthom (eds), *Disability and Psychology: Critical Introductions and Reflections*. London, Palgrave, pp 94-107.
- Rice, C. (2009) 'Imagining the other? Ethical challenges of researching and writing women's embodied lives', *Feminism and psychology*, vol.19, no.2, 245-266.
- Rickell, A. (2006) 'Key notes', *Disability Now*, 20<sup>th</sup> January 2006.
- Saldana, J. (2003) *Longitudinal Qualitative Research: Analyzing Change Through Time*. Walnut Creek, California, AltaMira Press.



Samuels, E. (2003) 'My body my closet: invisible disability and the limits of coming out discourse', *GLQ: A Journal of Lesbian and Gay Studies*, vol. 9 no.1-2, pp 233-256.

Segal, L. (1994) *Straight Sex: Rethinking the Politics of Pleasure*, Virago, California University Press.

*Sex on Wheels* (2013) Channel 4, 10<sup>th</sup> May.

Shakespeare, T. (1996) 'Disability, Identity and Difference', in C. Barnes and G. Mercer (eds) *Exploring the Divide: Illness and Disability*. Leeds, The Disability Press.

Shakespeare, T. (2006) *Disability rights and wrongs*, New York, Routledge.

Shakespeare, T., Gillespie-Sells, K. and Davies, D. (eds) (1996) *The Sexual Politics of Disability*. London, Cassell.

Sherry, M. (2004) 'Overlaps and Contradictions between Queer Theory and Disability Studies', *Disability & Society*, vol. 19, no.7, pp 769-84.

Shildrick, M. (2005) 'Silencing Sexuality: The Regulation of the Disabled Body' in J. Carabine (ed), *Sexualities, Personal Lives and Social Policy*, Buckinghamshire, Open University Press.

Shildrick, M. (2012) *Dangerous Discourses of Disability, Subjectivity and Sexuality*, New York, Palgrave MacMillan.

Shilling, C. (1993) *The Body and Social Theory*, London, Sage.

Shuttleworth, R. (2002). 'Defusing the adverse context of disability and desirability as a practice of the self for men with cerebral palsy', in M. Corker & T. Shakespeare (eds), *Disability and postmodernity: Embodying disability theory*, London, Continuum, pp 112-126.

- Skeggs, B. (1994) 'Situating the Production of Feminist Ethnography' in M. Maynard & J. Purvis (1994) (eds) *Researching Women's Lives*, Basingstoke, Taylor & Francis, pp 72-93.
- Skeggs, B. (1997) *Formations of Class and Gender: Becoming Respectable* London, Sage.
- Skeggs, B., Wood, H. & Thumin, N. (2009) 'Moral Economy of Person Production: the Class Relations of Self-Performance on 'Reality' Television', *Sociological Review*, vol. 57, no.4, pp 626-644.
- Smart, C. (1992) *Regulating womanhood: Historical essays in marriage, motherhood and sexuality*, London, Routledge.
- Smeaton, D. and Marsh, A. (2006) 'Maternity and Paternity Rights and Benefits: Survey of Parents 2005', *Employment Relations Series No 50.*, Department for Work and Pensions.
- Sothorn, M. (2007) 'You could truly be yourself if you just weren't you: sexuality, disabled body space, and the (neo)liberal politics of self-help', *Environment and Planning D: Society and Space*, vol.25, pp 144-159.
- Stables, J. and Smith, F. (1999) 'Caught in the 'Cinderella Trap': Narratives of Disabled Parents and Young Carers', in Butler, R. and Parr, H. (eds) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*, London, Routledge.
- Stanley, L. & Wise, S. (1983) *Breaking Out: Feminist Consciousness and Feminist Research*. London, Routledge.
- Strathern, M. (2003) 'Still giving nature a helping hand? Surrogacy: a debate about technology and society', in R.Cook, S. Day Sclater, F. Kaganas (eds), *Surrogate Motherhood: International perspectives*, Oxford/Portland Oregon, Hart publishing.

Strauss, A. and Corbin, J. (1998) *Basics of qualitative research* (2<sup>nd</sup> ed.), Thousand Oaks, California, Sage.

Swain, J. and French, S. (2000) 'Towards an affirmation model of disability', *Disability and Society*, vol.15, no.4, pp 569-582.

Tarleton, B., Ward, L. and Howarth, J. (2006) *Finding the right support: a review of issues and positive practice in supporting parents with learning difficulties and their children*, London: The Baring Foundation. (Online) Available at: [www.baringfoundation.org.uk/publications](http://www.baringfoundation.org.uk/publications) (Accessed 12/07/2011).

Thomas, C. (1997) 'The Baby and the Bathwater: Disabled Women and Motherhood in Social Context', *Sociology of Health and Illness*, vol.19, no.5, pp 622-43.

Thomas, C. (1999) *Female Forms: Experiencing and Understanding Disability*. Buckingham, Open University Press.

Thomas, C. (2004) 'How is disability understood? An examination of sociological approaches'. *Disability and Society*, vol.19, no. 6, pp 569-583.

Thomas, C. (2007) *Sociologies of Disability and Illness. Contested Ideas in Disability Studies and Medical Sociology*, Basingstoke, Palgrave Macmillan.

Thomas, C. and Curtis, P. (1997) 'Having a baby: some disabled women's reproductive experiences', *Midwifery*, vol. 13, pp 202-209.

Thomson, R. (2007) 'The qualitative longitudinal case history: practical, methodological and ethical reflections', *Social Policy and Society*, vol. 6, no.4, pp 571-82.

- Thomson, R. (2010a) 'Creating Family Case Histories: subjects, selves and family dynamics', in Thomson, R. (ed) *Intensity and Insight: Qualitative Longitudinal Methods as a Route to the Psycho-social*, Timescapes Working Paper Series, No.3.
- Thomson, R. (2010b) 'Using biographical and longitudinal methods: Researching motherhood', in Mason J. and Dale, A. (eds), *Understanding Social Research: Thinking Creatively about Method*. London, Sage Publications, pp 62-74.
- Thomson, R. and Holland J. (2003) 'Hindsight, foresight and insight: the challenges of longitudinal qualitative research', *International Journal of Social Research Methods* - Special issue on Longitudinal Qualitative Methods vol. 6, no.3, pp 233-244.
- Thomson, R. and Kehily, M.J., with Hadfield, L., Sharpe, S. (2008) *The Making of Modern Motherhoods: Memories, Representations and Practices*, ESRC Identities Report.
- Thomson, R., Kehily, M.J., Hadfield, L., Sharpe, S. (2009) 'The making of modern motherhoods: storying an emergent identity', in M.Wetherell (ed), *Liveable Lives: Negotiating Identities in New Times*, Basingstoke, Palgrave Macmillan.
- Thomson, R., Kehily, M.J., Hadfield, L., Sharpe, S. (2011) *Making Modern Mothers*, Bristol, Policy Press.
- Topp, J. (2005) 'Transitions through pregnancy: narratives of disabled women', *Disability, Pregnancy & Parenthood International*, 48: Winter 2004/2005.
- Tregaskis, C. & Goodley, D. (2006) 'Disability Research with Non/Disabled People: Towards a relational methodology of research production', *International Journal of Social Research Methodology*, vol.8 no.5, pp 364-374.
- Tyler, I. (2001) 'Skin-tight: Celebrity, Pregnancy and Subjectivity', in S.Ahmed, and J. Stacey (eds.), *Thinking Through the Skin*, Routledge, London and New York, pp 69-83.

- Tyler, I. (2008) 'Pregnant Beauty: Maternal Femininities under Neoliberalism' in R. Gill and C. Scharff (eds), *New Femininities: Postfeminism, Neoliberalism and Identity*, London, Palgrave.
- Walkerdine, V., Lucey, H., & Melody, J. (2001) *Growing up Girl: Psychosocial Explorations of Gender and Class*. London, Palgrave.
- Warren, S. and Brewis, J. (2004) 'Matter over Mind: Examining the Experience of Pregnancy', *Sociology*, vol. 38, no.2, pp 219-236.
- Watermeyer, B (2002) 'Disability and Psychotherapy: an Ideologically Charged Relationship in Community Mental Health Service Provision', in L. Swartz, K. Gibson, T. Gelman (eds), *Reflective Practice: Psychodynamic Ideas in the Community*, Cape Town: Human Sciences Research Council Publishers.
- Wates, M. (1997) *Disabled parents: Dispelling the myths*, London, National Childbirth Trust and Radcliffe Medical Press.
- Wates, M. and Jade, R. (1999) *Bigger than the sky: Disabled women on parenting*. London, The Women's Press.
- Watson, N. (2002) 'Well I know this is going to sound very strange to you, but I don't see myself as a disabled person: identity and disability', *Disability and Society*, vol.17, no. 5, pp 509-527.
- Watson, N., McKie, L., Hughes, B., Hopkins, D. and Gregory, S. (2004). '(Inter) Dependence, Need and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model', *Sociology*, vol. 38, no.2, pp 331-50.
- Wendell, S. (1996) *The Rejected Body: Feminist Philosophical Reflections on Disability*, London, Routledge.

- Wetherell, M. (ed) (2009) *Identity in the 21st Century: New Trends in Changing Times*. Basingstoke, Palgrave Macmillan.
- Williams, F. (2001) 'In and beyond New Labour: towards a new political ethic of care', *Critical Social Policy*, vol. 21, no. 4, pp 467-493.
- Williams, P. (1997) *Seeing a Colour-Blind Future. The paradox of race. The 1997 Reith Lectures*, London, Virago.
- Wilton, R. (2003) 'Locating physical disability in Freudian and Lacanian psychoanalysis: Problems and prospects', *Social and Cultural Geography*, vol. 4, pp 369-389.
- Wood, C. (2012) "For disabled people the worse is yet to come...." *Destination Unknown: Summer 2012*, London, Demos.
- Woodin, S. (2006) *Social Relationships and Disabled People: the impact of direct payments*, unpublished PhD thesis, School of Sociology and Social Policy, The University of Leeds.
- Yuval-Davis, N. (2006) Intersectionality and Feminist Politics', *European Journal of Women's Studies*, vol.13, no.3, pp 193-210.
- Zarb, G. (1997) 'Researching disabling barriers', in C. Barnes and G. Mercer (eds) *Doing Disability Research*, Leeds, The Disability Press.
- Zitzelberger, H. (2005) '(In)visibility: accounts of embodiment of women with physical disabilities and differences', *Disability and Society*, vol. 20, no. 4, pp 389-403.